The Model Reporting Area for Blindness

PROCEEDINGS OF THE 1968 CONFERENCE

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PROCEEDINGS OF THE 1968 CONFERENCE

May 23–24, 1968
Bethesda, Maryland

U.S. Department of Health, Education, and Welfare
Public Health Service • National Institutes of Health
National Institute of Neurological Diseases and Blindness
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CONTENTS

PAPERS PRESENTED TO THE CONFERENCE

Page

Program for improving MRA 1
ELDON L. EAGLES, M.D.

MRA's important unsolved problems 5
JOSEPH KOHN

Updating Virginia's MRA register in 1967 7
WILLIAM T. COPPAGE

Significant problems and uses of North Carolina's blindness register in 1967 9
SHERLEY BLACKBURN

Opportunities for twin studies in blinding disorders 11
J. THEODORE SCHWARTZ, M.D.

Maryland's progress toward MRA membership 17
GEORGE W. KELLER

Maintaining accuracy of your MRA State register between years 23
JAMES E. JOHNSON

Causes of blindness in 4,965 persons whom 14 States added to their MRA registers in 1966 27
A STAFF PAPER

The allocation of funds for providing services to the blind 39
GERALD ROSENTHAL, PH.D.

Stimulating eye examiners to report blindness to a State register 45
KARL W. STOCK, M.D.

Stimulation of blindness reporting 49
JOHN F. MUNGOVAN

Study of infants and young children with visual problems 53
ELIZABETH M. HATFIELD, M.P.H.

Rubella epidemiology and vaccines 61
JOHN L. SEVER, M.D.

Page

Implications of a functional definition of blindness 67
RICHARD E. HOOVER, M.D.

Social and rehabilitation services for the visually impaired 71
D. C. MACFARLAND, PH.D.

Economic benefits to the Nation from providing visual assistance devices to its blind 75
KENNETH TROUERN-TREND

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PROGRAM for IMPROVING MRA

ELDON L. EAGLES, M.D.[1]

LADIES AND GENTLEMEN, it is a great pleasure to welcome you to the 7th MRA conference. I sincerely hope that you will enjoy the program and that it will give you ideas for making MRA more useful.

To start this conference, I will outline for you our program to improve MRA. This program will have certain objectives which I will cite. Our highest priority objectives are long range and will require continuing effort by the National Institute of Neurological Diseases and Blindness (NINDB) and the MRA states.

First three objectives:

1. To eliminate weaknesses from MRA registers.
2. To stimulate blindness reporting.
3. To furnish adequate statistical assistance to MRA states.

Fourth and fifth objectives:

4. To improve the validity and reliability of statistics on blinding conditions and their causes.
5. To improve the annual statistical reports and proceedings for annual MRA conferences.

Sixth through ninth objectives:

6. To publish a manual giving detailed guidance on how to establish and operate an MRA register. A draft of this manual has been circulated to MRA states and you will discuss it next on this program.
7. To publish a manual for coding blinding conditions and their causes. It will supplement the present instruction manual on coding.
8. To publish an annual summary of MRA data. It will supplement present annual statistical report.
9. To publish a brochure describing MRA to the public to replace present brochure which is obsolete.

Many MRA registers have the following weaknesses:

1. They do not contain a record for every blind person.
2. They contain records which are incorrect, incomplete, or not current.

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[1] Assistant Director, National Institute of Neurological Diseases and Blindness, National Institutes of Health.

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3. They contain records that do not belong in the...
4. They are only partially comparable with each other.

NINDB will have its statisticians visit State blindness agencies to help correct these weaknesses, stimulate ophthalmologists and optometrists to report blind persons to State registers; to help remove records on those who are deceased, have recovered vision, departed from State, and those who cannot be located. Our statisticians will help State agencies with technical problems if they so desire.

A program to stimulate blindness reporting to State registers will be developed after we have analyzed responses of ophthalmologists and optometrists from 29 States concerning their attitudes on reporting their patients to State blindness registers.

A major goal in our program for improving MRA will be to improve the validity and reliability of MRA data on blinding conditions (site/type) and their causes (etiology).

When necessary, we use history and physical findings that are recorded in about half the eye examination reports we receive, to interpret imprecise diagnostic terms and to classify blinding conditions and their causes more precisely.

A major effort has been to reduce mistakes in classifying blinding conditions and their causes. We control such mistakes fairly well by coding for small States and reviewing coding of large States. Despite staff shortages we have reduced mistakes significantly.

We have also reduced wide variations between States in classifying blinding conditions and their causes that were common at MRA's beginning.

An index published in 1966 clearly defined blinding conditions. This index gave coding instructions for many more terms than the previous one, and prescribed arbitrary codes for some blinding conditions which formerly had been classified in a variety of categories as individual coders interpreted the classification system.

Each MRA statistical report published yearly since 1962 contains data primarily for a single year. It rarely compares current year with preceding years and has not analyzed trends. We have sufficient experience now to make trend studies. The 1966 statistical report is in preparation and we hope to make more useful than its predecessors. For example, we will define and explain data terms and categories used in the report. Such definitions have not been provided previously.

An MRA instruction manual covering the entire MRA program has been drafted and copies have been distributed for comment. This is an important attempt to improve the MRA, reduce confusion and make State registers more comparable.

An instruction manual will be prepared for coding visual impairment causes. It will supplement the National Society for the Prevention of

Blindness manual for coding such causes. In its January 1968 meeting the MRA Advisory Group agreed that this should be done.

A summary statistical report will be prepared for each current year as soon as staff time becomes available for this purpose. This report will highlight and summarize significant MRA data for a year. The MRA Advisory Group at its meeting in January 1968 suggested that such a report be prepared annually for wide distribution, including ophthalmologists who dislike the present detailed statistical report. We will continue to publish the detailed report however, because there is a demonstrated need for it.

A new brochure will be prepared describing the MRA not only for the public in general, but also for the sources that report persons to State blindness registers. This new brochure will replace the present one which is obsolete.

MRA'S IMPORTANT UNSOLVED PROBLEMS

JOSEPH KOHN [1]

YOU KNOW that the Model Reporting Area (MRA) for Blindness Statistics has been faced with many problems some of which have been solved. The purpose of this presentation is to discuss some of the important unsolved problems that we should give attention to.

The percent of the blind population that is not reported for registration needs to be estimated or determined. The reasons why every blind person does not need to be registered have been discussed in previous MRA conferences. It is important to remember that our major goal should not be to register every blind person. Instead, it should be to measure what percent of them have not been registered. This percent figure should be estimated separately for every MRA State so that each State's blindness agency could determine what percent of the blind population it is serving.

The MRA member States, in cooperation with the National Institute of Neurological Diseases and Blindness (NINDB) should decide what additional medical information should be added to the MRA record for a blind person. More than 50 percent of the blind adults and children receiving services from us here in New Jersey are multihandicapped.

More research should be performed on blinding affections and their etiologies. We have barely scratched the surface of this issue. Several of us State directors of blindness agencies have made presentations concerning this need to NINDB's Director and its Assistant Director.

NINDB should send a statistician to each MRA State at least once each year to review and discuss the State's MRA program. This was done in previous years and should be reinstated as soon as sufficient resources become available for this purpose.

The MRA and the U.S. Public Health Service should cooperate more closely so that Public Health representatives can relate and apply significant MRA findings in the programs they sponsor and support in several States.

Each MRA member State should cooperate with individuals and organizations which are conducting research on blinding affections and their etiologies. For example, we in New Jersey are cooperating with a local opthalmologist who is studying vision loss from traumatic accidents and with the National Society for the Prevention of Blindness in its study of infants and young children with visual problems.

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[1] Executive Director, New Jersey State Commission for the Blind.

UPDATING VIRGINIA'S MRA REGISTER in 1967

WILLIAM T. COPPAGE [1]

WE UPDATED our Model Reporting Area (MRA) register for the first time in 1967. It had 5,731 persons on December 31, 1966, and we contacted 3,306 of them in 1966 while providing services to them in that year.

To the 2,425 persons in the register whom we had not contacted in 1966, we sent, on June 13, 1967, a form letter and a prepaid self-addressed postal card to be returned to us. We wrote to 748 of them on July 13, and to 566 on August 17.

We cleared as active the 1,219 persons who responded to these mailings, and we removed from the register 291 persons whom their family or postal authorities reported as deceased. No response was received from 465 persons and the postal authorities could not locate 458 of them.

Our field staff, particularly rehabilitation teachers, attempted to contact the 465 persons who did not respond to our mail inquiry, and located 164 of them whom we cleared as active. We removed from our register the 301 persons our field staff could not find and the 458 whom the postal authorities could not locate. Upon adding these 759 removals to the 291 whom we removed because of death, it is seen that 1,050 persons were removed from our register in 1967.

We will update our register again in 1968 and expect to contact by mail only 1,436 persons compared with 2,425 in the 1967 updating. In 1968 we expect to locate all the 1,436 persons to be contacted because in 1967 we had removed practically all the deadwood from our register.

In 1967 we furnished materials to 191 ophthalmologists and eye-ear-nose-and-throat specialists and 205 optometrists to inform and encourage them to report all legally blind persons to us. These materials were the National Institute of Neurological Diseases and Blindness report containing statistics for 1965 blindness in the MRA, our brochure which describes services we provide to blind persons, and a supply of revised forms for reporting results of eye examinations to us. These eye examiners have informed us that they were glad to receive these materials.

---

[1] Director, Virginia Commission for the Visually Handicapped.

SIGNIFICANT PROBLEMS and USES of NORTH CAROLINA'S BLINDNESS REGISTER in 1967

SHERLEY BLACKBURN [1]

OUR PRIMARY PROBLEM in 1967 was to code affections of the visual system and their causes (etiologies) properly. The State's registrar of the blind has completed a graduate course in eye diseases so that she could improve this coding.

Another problem was to get case history from the various reporting sources for persons whose visual system required medical treatment from an ophthalmologist. Our increased social service staff was able to contact each registered person at least once during the year. Case history information also was obtained from statewide clinics, ophthalmologists, etc.

The blindness register was used in a variety of ways in 1967. It provided statistics on blindness for inclusion in the Official Biennial Report to the Governor. The case histories of blind children under age 7 were given to the National Society for the Prevention of Blindness to help it determine the current primary cause of blindness in preschool age children which has replaced Retrolental Fibroplasia, the previous primary cause. The total number of legally blind persons who receive aid to the blind assistance in North Carolina and the number of these that were Indians were provided to the Public Health Service.

The number of children blinded from the mother's German Measles was kept under surveillance to determine whether an epidemic was imminent to insure that additional and any different services which may be required could be obtained in time.

We furnished to the Duke University Medical School information on registered persons blinded by corneal atrophy so that changes in the disease and its destruction of visual capability could be measured. The North Carolina State Department of Administration was furnished data on the number of registered blind by age groups, race, sex, and number of aid-to-blind recipients for use in planning a comprehensive health program for the State.

MRA information was valuable in 1967 not only to the State for management of its blindness programs, but also to the National Institute of Neurological Diseases and Blindness for preparation and publication of statistics on blindness required at the national level.

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[1] Supervisor, Social Service Division, North Carolina State Commission for the Blind.

OPPORTUNITIES for TWIN STUDIES in BLINDING DISORDERS

J. THEODORE SCHWARTZ, M.D.[1]

THE STUDY OF TWINS, an effective research tool in human genetics, has been used little in eye research, particularly in the United States, probably because it is thought large twin populations are difficult to find. However, we have located over 500 pairs of twins in the Washington Metropolitan area with little effort and expense.

Since the structure and function of the visual system can be observed precisely, it is unfortunate that ophthalmic investigators have not made greater use of twin study methods. This paper reviews how blinding disorders and ocular characteristics could be studied with twin-study methods. It mentions how investigators could unify their efforts to locate twins with ocular abnormalities.

Twin research describes the heritability of a trait. Figure 1 reviews the principle underlying heritability studies. Since identical (ID) or monozygotic (MZ) twins are derived from the cleavage of a single fertilized egg, they are assumed to be genetically the same. On the other hand, fraternal or dizygotic (DZ) twins, from the separate fertilization of two eggs have no more genetic relationship than a pair of offspring from the

TERMS AND DEFINITIONS

HERITABILITY . . . . . That Portion of Total Variance in a Trait That is Due to Genotypic Variance

MONOZYGOTIC TWIN (MZ TWIN) (IDENTICAL TWIN) . . . . Like Sex . . . . Genetically Identical

DIZYGOTIC TWIN (DZ TWIN) (FRATERNAL TWIN) . . . . LIKE SEX OR UNLIKE SEX . . . Genetically Non-Identical

CONCORDANCE . . . . . Presence of Same Trait in Both Members of a Pair (MZ or DZ)

IF . . . . . Concordance MZ (CMZ) > Concordance DZ (CDZ)

THEN . . . . Significant Hereditary Component Exists

FIGURE 1

[1] Head, Section on Ophthalmic Field and Developmental Research, Collaborative and Field Research, National Institute of Neurological Diseases and Bindness, National Institutes of Health.

same parentage. Cotwins of either type (identical or fraternal) are likely to share a similar physical cultural and biologic environment.

The approach to twin studies is straightforward. In an investigation of a disease process, ID and non-ID twins are identified wherein one member of each twinship is known to be affected. The cotwins of these known cases are then examined. The concordance rate, the percent of agreement among pairs of twins, is calculated for both twin types and the two concordance rates are compared. If a given trait or disease is more common in both members of ID twinships than it is in both members of non-ID twinships (i.e., if the ID twins are more commonly "concordant" for the trait than are the non-ID pairs), the disease under study has some genetic determination. If the concordance rate of ID twins approaches 100 percent while the non-ID twins have a significantly lower rate the transmission of the disease is genetic exclusively.

Only like-sex pairs of non-ID twins are used usually in a concordance comparison with the ID pairs because like-sex non-ID twins often share a more similar environment than cotwins of unlike-sex. When the disease occurs relative to characteristics such as age or sex it is important to compare concordance for twin populations which are similar with regard to such characteristics.

Figure 2 demonstrates some of the methods of employing twin data to estimate the relative roles of heredity and environment in determining the presence or absence of an investigated disease. The relative role of heredity and environment on a percent scale can be estimated. For example, concordance rates can be used as input information in formulations which express the roles of heredity and environment in a Heritability Index (H.I.) which varies from 0 to 1. Hereditary influence increases as the calculated H.I. approaches unity. Conversely, low H.I. values reflect a strong environmental influence.

Heritability estimates do not define a specific mode of genetic transmission such as dominant and recessive. This requires investigations such as pedigree analysis and family population studies.

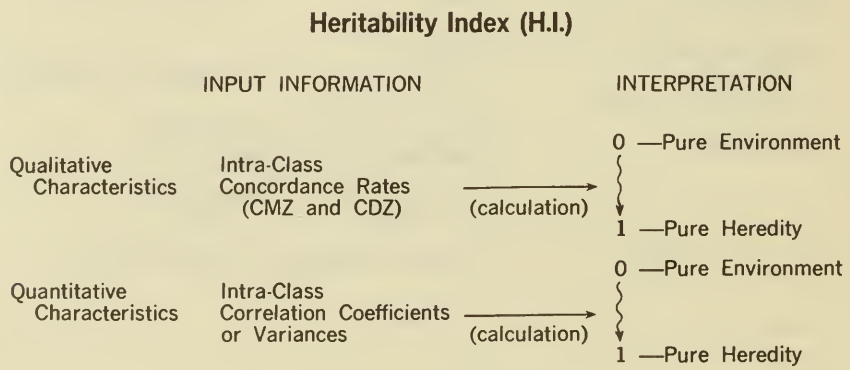

FIGURE 2

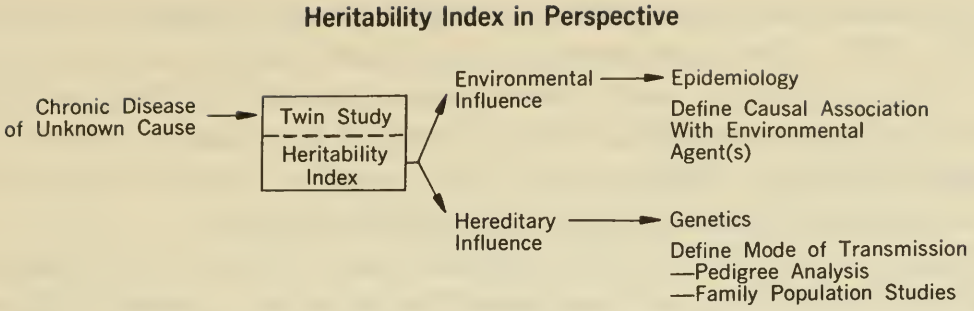

FIGURE 3

Figure 3 illustrates the unique role of twin studies in investigating the cause of chronic disease. The causes of most important chronic diseases which lead to blindness are poorly understood as they show no simple Mendelian pattern and are not associated with an obvious environmental agent. This is the precise situation wherein estimates of heritability are most valuable. In this perspective, twin studies can identify lines for productive further investigation into the cause of a disease. Thus, twin heritability studies can precede and lend direction to more detailed genetic or epidemiologic study.

The relative contribution of heredity and environment in ophthalmic disorders is unknown for most common chronic affections. It is unknown even for frequent blinding disorders such as cataract and macular degeneration. The inheritability of chronic simple glaucoma, a common cause of blindness in the United States, is currently debated. Some have suggested that it is transmitted via a simple autosomal genetic mechanism (*1*). Their hypothesis is based on studies of responsiveness to a steroid type of eye drop. This medication increases intraocular pressure in some instances. When used on family members of glaucoma cases and when used on the general population, the proportion of responsiveness appears consistent with the expectation from the genetic hypothesis.

Other observers using similar investigation methods cannot verify this hypothesis (*2, 3*). It will be valuable to reappraise with a careful twin study, the hereditary strength in transmission of the hypertensive steroid response. This question stimulated the beginning of our local twin registry.

Beyond disease processes, little is known of the inheritance of variations in ocular anatomy and function, including changes commonly associated with aging. Measurements of ocular motility aspects such as phoria, convergence power, and divergence power are other examples of "normal" variables which might be studied for heritability via examination of twins.

Any visual system characteristic which varies measurably is suitable for a heritability study of the "normal." An investigation of "abnormal" conditions is limited primarily by our ability to identify affected twinships in sufficient numbers.

Heritability estimates are only one of the unique applications of twin studies. This is the classic method of study and it has been discussed first and most extensively only because it is a convenient reference frame. Other applications may lead to the recovery of more useable information. Three additional examples will be mentioned. Each requires the ascertainment or identification of affected ID twinships.

Case-control studies of monozygotic twins are useful for clinical investigations and may be unsurpassed by any other approach. Figure 4 illustrates the general plan of such case-control design. ID twins concordant for a given characteristic or disease are identified, one member of each twinship is subjected to an altered environment such as a treatment, while the other member is the control.

The low likelihood of locating twinships with a specified disease is the main weakness of the case-control method. If ophthalmologists or others developed a coordinated case register for ID twins having specific ocular disorders, adequate numbers of twins might be ascertained for definitive case-control investigations. Specific studies could be designed and executed cooperatively.

A practical point in question today is the suspected impact on the progression of near sightedness from cycloplegic drugs, bifocal lenses or contact lenses. Some feel that bifocal lenses and certain medications retard the progression of myopia. If sufficient numbers of nearsighted ID twins can be identified, one member of each pair might be maintained with full spectacle correction while the other member is provided the specific variation in treatment as desired. The twins could be followed prospectively to appraise the outcome. If ID twins with diabetic retinopathy can be ascertained, the uncertainty of its medical or surgical treatment might be reduced.

The unique advantage of using identical twins for case-control studies is the unusually close genetic and environmental match between manipulated and control cases. When the study population for a case-control

Case Control Study With Twin Subjects

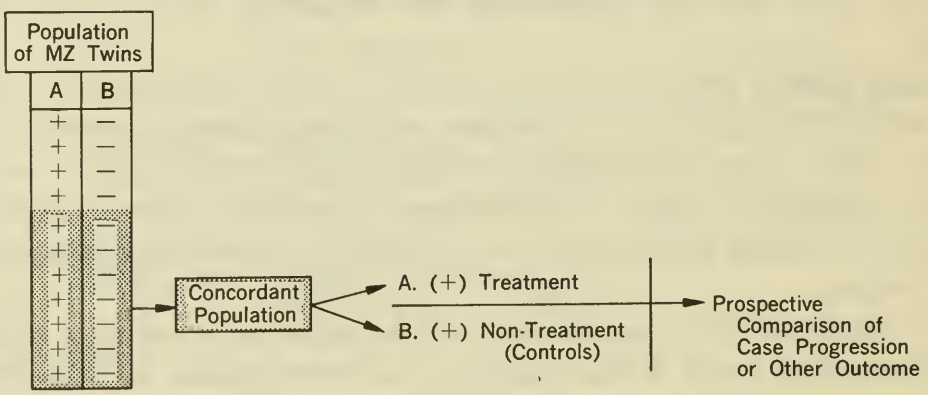

FIGURE 4

experiment is drawn from concordant monozygotic twinships the outcome should be altered almost solely by the experimental factor. Such studies can be designed to be very sound methodologically.

How twin studies can help define the natural history of a chronic disease is illustrated in Figure 5. A disease which heredity influences moderately or strongly should have a high concordance rate among monozygotic pairs. However, the disease does not have to occur at the same point in time for both twins. One is likely to identify discordant monozygotic cotwins who ultimately will become concordant for a disease but who are not yet both affected. This is an opportunity to observe closely the unaffected cotwin of the propositus or original case to learn the early natural history of a chronic disease.

This twin study method is applicable in investigations of chronic simple glaucoma. Our knowledge of its natural history is very insecure. If ophthalmologists could find monozygotic twinships discondant for chronic simple glaucoma, they might be able to define its incipient state and earliest progress by prospective examination of unaffected cotwins. This would require relatively little money and professional time.

The twin method permits epidemiologic studies of environmental agents which cause disease. Such effort identifies environmental factors which influence the expressivity of a "genetic" disease. Figure 6 illustrates a search for a contrasting environmental experience among affected and nonaffected ID twins. If an environmental factor can be identified, its association with expression of the disease might be evaluated further by searching for the same factor in both members of the ID pairs concordant for the disease. Twins concordant for the disease should be highly concordant for the suspected environmental factor.

Such study design could investigate the so-called "use-abuse" theory of development of progressive myopia. Present knowledge expects a moderately high concordance rate for high myopia among MZ twins. The reading habits, etc., of cotwins of the remaining discordant pairs could be compared.

Use of Twin Studies to Define the Natural History of a Chronic Disease Through Ascertainment of High Risk Subjects

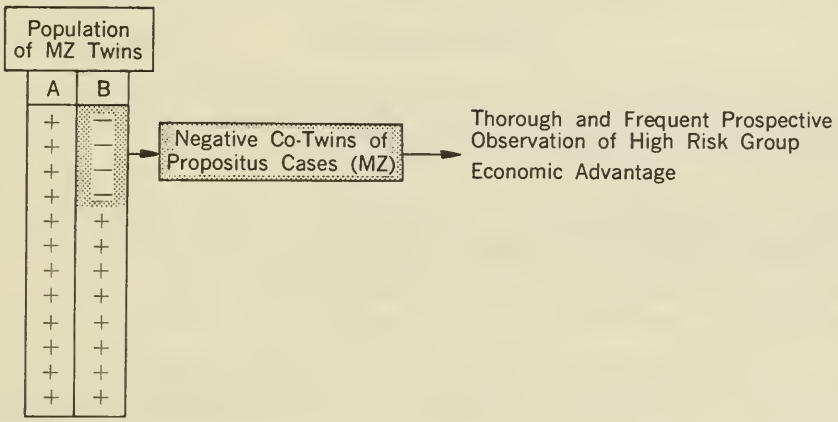

FIGURE 5

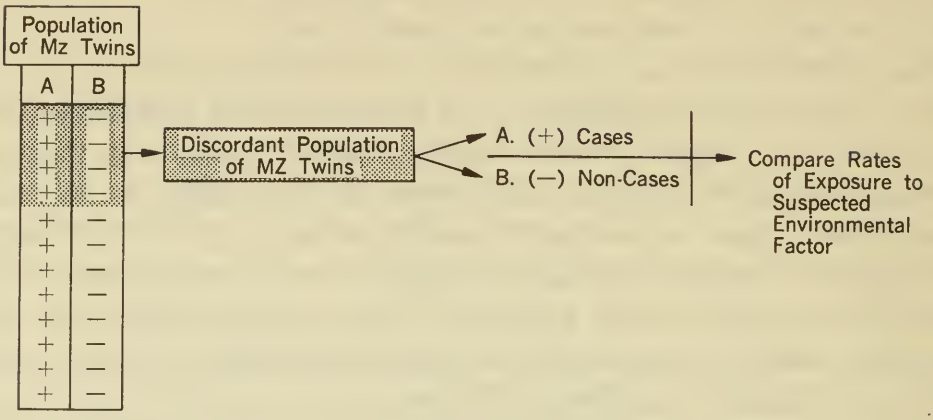

FIGURE 6

In a purer interpretation of epidemiologic applications the primary interest is in geographic differences in the disease frequency and concordance rates among twins. In such investigations, twins are studied in different parts of the world where contrasting observations due to different genetic pools or different environments might be informative (*4*). This type of investigation has not been tried on a wide scale.

This discussion of twin studies is ended with the following remark of the moderator at the "Conference on Problems and Methods in Human Genetics" held in Bethesda, Md., in 1953 (*5*).

> "If an individual or foundation with large sums of money were looking for advice on how it should be spent to learn the most possible about human variation, I believe we would recommend that it should be spent on human twin studies."

Twin studies have not found their rightful place in research on blinding disorders. Ophthalmologists can make more varied and more definitive observations on structure and function than any other medical specialty. If investigators cooperated in establishing twin registers, or in developing a reporting system for affected MZ twinships, they would have a valuable resource for productive investigations.

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MARYLAND'S PROGRESS TOWARD MRA MEMBERSHIP

GEORGE W. KELLER [1]

THE NATIONAL INSTITUTE of Neurological Diseases and Blindness (NINDB) awarded Maryland a contract in summer 1966, to be completed by December 31, 1967, to establish a register of the legally blind so that Maryland could become a member of the Model Reporting Area (MRA) for Blindness Statistics. A staff was recruited for this project by January 1967 and actual registrations were started then. Since this put us 6 months behind schedule, NINDB, upon our request, extended the contract to June 30, 1968.

We have collected information under this contract on nearly 4,000 persons believed to be legally blind. The ophthalmological data available on about 2,000 of them is sufficient to meet MRA standards. At present 1,000 have been coded and are in our Data Processing Section where cards are being punched. Code sheets are being completed on an additional 500 and will be forwarded to Data Processing by end of May. Another 500 with eye information should be coded by July and ready for punching.

About 800 who have been reported to us with eye information cannot be located to verify that they live in the State. We have established that some of them have died and others have left the State.

Some information has been received on another 1,000 persons for whom we do not have eye information to prove legal blindness. We began contacting persons in July 1967 who had been referred to us. A descriptive list of services for the blind was mailed to each individual with a letter explaining the Register's purpose and NINDB participation, and a postcard for the individual to sign giving us permission to obtain information on their eye condition.

There was a 30 percent response to the first mailing, and subsequent mailings increased our returns to over 50 percent. After we changed the project's name from "State Register of the Blind" to "State Register of the Blind and Visually Impaired," about a year ago, more partially sighted persons were willing to be registered and responded favorably to our inquiry.

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We have explored all sources which might ref blind persons to the register, beginning with agencies which provide services to the blind. Our part-time clerical personnel abstracted information from files of the Maryland School for the Blind and the Maryland Workshop for the Blind for several months.

At the Maryland School for the Blind, it was decided only to register those persons who had attended the Institute since 1900. Records of more than 1,000 persons were abstracted. Except for recent years, only the student's application for admission contained eye information. There was no separate eye report as such. The school will refer to us at the beginning of each year all of its new students and all preschool cases visited by their social worker.

At the Maryland Workshop for the Blind records were examined on 5,000 persons with whom there had been some contact. The records of the Home Teaching Department, the Talking Book Department, and the Workshop Department, in some cases duplicate each other. We eliminated a few persons who were not legally blind. More than half the records contained no eye information. Home teaching has served most of these persons. The Workshop recently decided that it will take applications for their program on our Register Referral Forms. This will expedite information flowing to us.

The State Department of Public Welfare has forwarded information to us on all persons receiving aid to the blind through county welfare agencies. Eye information has accompanied the referral in every case. However, some public welfare recipients cannot be identified for referral to us because they are receiving help under Aid to the Permanently and Totally Disabled.

The State Department of Health has referred only a few persons to us. We should receive information on children seen in eye clinics of county health departments. School programs and other sources refer some of these to us.

The Special Education Program, another division of our Department, has provided us a list of legally blind students in public schools, which is compiled annually to validate their requests for reading materials from the American Printing House for the Blind. The County Boards of Education have been reluctant to provide us with information on these students. Most eye reports were obtained from ophthalmologists or hospitals which examined the students. Many school systems have eye reports on these students, and we could get them if we insisted. We prefer to have the approval of the student's family.

The Division of Vocational Rehabilitation, and its Disability Determinations Branch, which clears applicants for disability under Social Security, refer blind persons to us. Most eye reports are complete, and we request that counselors refer these cases to us when they are accepted for rehabilitation.

The Chief of Ophthalmology at the University of Maryland Hospital has referred blind persons to us. However, Social Service and other areas of the Hospital have not been so cooperative. Johns Hopkins Hospital has referred blind persons to us from its Social Service Department, Optical Aids Clinic, and ophthalmologists who serve the hospital. It also has permitted us to abstract information on legally blind patients after such persons have given their permission. Nevertheless, we receive information only on a small percentage of the persons in the various services and departments within the Hospital. A person trained in working with blind persons will be added to their Occupational Therapy staff to provide information to the blind on services available to them, and to counsel blind persons on personal adjustment, skills of daily living, communication skills, and mobility. Since this person will work with our Rehabilitation personnel, and probably will see most blind persons visiting Johns Hopkins, we expect referral from this source to increase.

Other hospitals that have referred blind persons to us are the Greater Baltimore Medical Center; Baltimore Eye, Ear, Nose and Throat Hospital; Sinai Hospital; the VA Hospital at Perry Point; and several State Hospitals.

Our blindness registrar and a clerical assistant have reviewed the records of more than 400 visually impaired persons at Rosewood State Hospital for the Mentally Retarded. Over 200 were legally blind. There are 3,000 persons at this Hospital, and if at least 200 are legally blind, the blindness prevalence rate is about 7 percent. This is not surprising, since physical disabilities often accompany mental retardation.

Private Ophthalmologists refer new patients to us but not their former patients. They have furnished us diagnostic information when we requested it for persons whose permission had been obtained.

Optometrists have referred only a few persons to us, but they probably do not see many legally blind persons. We need to educate ophthalmologists and optometrists to refer their blind patients to us routinely.

We have had the same problems that other States have faced in establishing their MRA Registers. Our staff was at the onset not adequate. A full-time registrar, at the rehabilitation counselor level, a clerk-typist, and secretary half-time, were thought to be adequate. It soon was evident that part-time abstracters of information from the files of large agencies should replace the secretary. The clerical work our registrar had to do limited her time for publicizing the Register, and personally contacting referral sources. Other secretaries in the Rehabilitation program were most helpful in assisting with the work. We should have had at least two or three full-time clerical workers in addition to our registrar, and part-time personnel on the outside.

Vocational Rehabilitation Counselors and Home Teachers helped to locate persons whose records appear in old files of the Maryland School and Maryland Workshop for the Blind who were difficult to find. Until

now, our Home Teaching Program has operated from a separate agency, and we could not use the teachers fully on the Register. On July 1, 1968, the Home Teaching Program, which has operated from the Maryland Workshop for the Blind, will be transferred to the Division of Vocational Rehabilitation. Home Teaching has been supported entirely by State funds since 1947, and has functioned under an agreement between the State Department of Education and the Maryland Workshop for the Blind. The program was closely identified with Vocational Rehabilitation in this period; but because it has been administered by a separate agency, we could not coordinate the program satisfactorily with Rehabilitation. The transfer of eight professional workers from Home Teaching to our Department will enhance the Rehabilitation Program and facilitate the progress of our Register. A most compelling reason for the transfer is that it will enable us to expand Home Teaching with Federal funds.

Some persons have been reluctant to have their names on the Register, partly because of the way in which our release was worded. We asked them to let us obtain information that the State Register of the Blind and Visually Impaired needed to promote research in disability. The word "research" bothered some. Their permission usually was given to us upon further explanation. We have changed the statement to request permission to obtain information on the eye condition.

The Register project has yielded many positive results. The Vocational Rehabilitation Program until now has not been particularly identified as a service for the blind. The Register is changing this. Since both individuals and agencies call upon us for information, we are becoming the focal point in the State for Services for the Blind. When the Home Teaching Program is transferred to our Division, the State Department of Education will encompass practically all Services for the Blind.

The State Department of Education is now preparing to offer library services to the blind. This service was formerly provided by the Regional Library at Richmond, Va. The Register will help in locating other blind persons who desire this service. Referrals are first screened by our Register. Often we do not have sufficient information to determine whether an individual is a candidate for rehabilitation. However, when necessary, rehabilitation counselors conduct further investigations to determine the eligibility and feasibility of the applicant.

Our Register has been helpful in several ways. For example, the Maryland Workshop for the Blind has a subcontract job on which they must use blind persons with at least one or more disabilities in addition to blindness. From the Register we developed a list of 110 such individuals and 35 or 40 are being trained or employed in the Workshop. A Doctor at Johns Hopkins University wanted information concerning the number of blind persons whose eye conditions were hereditary. The Register showed that about 20 percent of the 1,483 persons registered had such conditions. We also gave him a breakdown concerning condition types.

A study at Rosewood State Hospital for the Retarded located 200 legally blind persons. Thirty-seven of these have been screened to determine their potential for vocational rehabilitation. The Personnel Research Center of Philadelphia has been retained for psychological evaluation of the group. Such evaluations administered when persons were placed in the Hospital were not always valid because of vision loss. The Vocational Rehabilitation Unit, which has operated in the Hospital for 2 years, is preparing a research project which will study vocational rehabilitation possibilities for the legally blind.

We have reached the halfway point in establishing our Register. There probably are 6,000 to 7,000 legally blind persons in the State, and we have obtained information on about 3,800. Even though we have not located all these persons, or secured necessary information for registering them, we have made good progress since the project began 18 months ago. After our contract ends on June 30, 1968, we will continue to register blind persons with a full-time clerk. A professional worker will direct and supervise the project.

Without NINDB's help and guidance, we might not have established a Register of the Legally Blind which already has helped the program of services to the blind. Even though our Register is incomplete, we probably know more about blindness than any other disability.

MAINTAINING ACCURACY of YOUR MRA STATE REGISTER BETWEEN YEARS

JAMES E. JOHNSON [1]

EACH YEAR you send us punched cards which reflect the status of your register on December 31. What changes take place in your register between the end of one year and the end of the next? First, you add some new cases to your register, and secondly, you remove some cases from it. If your work is accurate, your register on December 31 of the current year will balance with your register on December 31 of the previous year. Taking calendar year 1967 as an example, your register balances for 1967 if:

Total on register as of December 31, 1966
+ Cases registered in 1967
− Cases removed in 1967
= Total on register as of December 31, 1967

For example, if the total on your register as of December 31, 1966, is 100 and you added 10 persons, and removed 5 persons in 1967, the register balances if the total on register as of December 31, 1967, is 105 . . . since in fact, 100+10−5=105.

Suppose the total on your register taken from the punched cards submitted for December 31, 1967, is 104 or 106. Now the register does not balance for 1967 . . . since 100+10−5=105, not 104 or 106. As you can see from Tables 1 and 2, some State registers do not balance.

Turn to Table 2 and find the name of your State on the left side of the page. Now move to the first numbered column. This column represents the total of your register on December 31, 1966. The next column represents the cases you added to your register in 1967. The column after that represents the cases you removed during 1967. Column 4 represents the number we expect to find on your register from your 1967 punched cards and is equal to column 1 plus column 2 minus column 3; or the register at the end of 1966 plus 1967 additions and minus 1967 removals. Column 5 is the number on the register at the end of 1967 as taken from the punched cards you sent us at the end of 1967. Column 6 is the difference between columns 5 and 4 or the difference between the number of

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cards we actually received from you at the end of 1967 and the number we expected to receive. What could cause your register to be out of balance?

Assume that you added a person to the register in 1955 with cataract as the blindness cause. An operation restored sight, and in 1957 you received an eye exam which indicated visual acuity in the better eye exceeding 20/200. You then removed this person from your register. Glaucoma was reported in 1967 and you readded the person to the register coding type of addition as readdition. If you still show 1955 as the registration year, your register will not balance since you will not know that this person did not appear on the register in the years 1958 through 1966. You should make 1967 the registration year. This points out an important principle of MRA registration:

1. When you assign a registration date, treat first additions and readditions alike. Distinguish a first addition from a readdition with the type of addition code, and not by means of the registration date.

Now complicate this example. Suppose the person was reported to you in December 1955, with cataract as blindness cause and you added the person to your register in January 1956. Enter a registration date of January 1956, the date when you actually made the registration and not December 1955, when the person was reported to you. An operation restored sight and in November 1957 you received an eye report indicating visual acuity of better than 20/200 in the better eye. The supervising ophthalmologist reviewed this report in February 1958, and in March you removed the person from your register. You should use March 1958 as the removal date, reflecting the date when the removal was actually made. Do not use November 1957, the date sight was restored, and do not use February 1958, the date the report was reviewed. In December 1967, glaucoma was reported and in January 1968, you readded the person to the register with registration date of January 1968, not December 1967. Note that in each instance you received the report late in a year and took no action until early in the next year. If registration and removal dates are not given as the dates when the work of registering and removing this person are actually done, your register will not balance between years. This illustrates a second important principle:

2. Use registration and removal dates which reflect the time you actually register and remove persons from the register.

To take a different example, suppose a person was registered in 1966 and birth year was reported to be 1900. You discover in 1968 that this

birth year is wrong and that the correct birth year is 1920. While correcting birth year, you change the registration date to 1968 to reflect the last time you modified the punched card. This is a mistake, as once a person is registered, the registration date remains the same unless the person is readded after a removal. Therefore, the third registration principle is:

3. Once a registration date has been assigned, do not change it. The one exception is when a person is readded after having been removed from the register. Do not change the registration date when you record a change in demographic or medical information.

Finally, suppose that a person was added to the register and you later discover that his visual acuity was not less than 20/200 and visual field was not restricted. In other words, he never met the visual criteria for inclusion on the register. The normal removal process as described above requires recording the removal date as the actual date you remove a person. Here, rather than remove by the regular process a person who never really belonged on the register in the first place, it is decided to destroy the registration card. This incorrect procedure throws the register out of balance. The removal code "other (administrative error)" is designed to handle this case. Therefore, the final principle of registration is:

4. Once a person is on the register, he may be removed only through the normal removal process. Cases added in error are removed by the normal process reflecting the error in the removal code.

In summary, you will keep your register in better balance between years if you follow these four principles:

1. When you assign a registration date, treat first additions and readditions alike. Distinguish a first addition from a readdition with the type of addition code, and not by means of the registration date.
2. Use registration and removal dates which reflect the time you actually register and remove persons from the register.
3. Once a registration date has been assigned, do not change it. The one exception is when a person is readded after having been removed from the register. Do not change the registration date when you record a change in demographic or medical information.
4. Once a person is on the register, he may be removed only through the normal removal process. Cases added in error are removed by the normal process reflecting the error in the removal code.

TABLE 1.—*Register Accurary Between December 31, 1965 and December 31, 1966*

MRA State	Total on register as of Dec. 31, 1965 (1)*	Additions during 1966 (2)	Removals during 1966 (3)	Expected total on register as of Dec. 31, 1966 (4)	Actual total on register as of Dec. 31, 1966 (5)	Difference between expected total and actual total (6)
Conn	3, 256	403	260	3, 399	3, 402	+3
Kans	3, 263	379	343	3, 299	3, 299	0
La	6, 027	380	297	6, 110	6, 110	0
Mass	9, 713	1, 011	983	9, 741	9, 741	0
N.H	1, 039	143	138	1, 044	1, 048	+4
N.J	7, 408	636	737	7, 307	7, 295	−12
N. Mex	2, 606	67	154	2, 519	2, 532	+13
N.C	10, 114	1, 157	867	10, 404	10, 383	−21
Oreg	2, 331	453	298	2, 486	2, 489	+3
R.I	1, 097	79	92	1, 084	1, 086	+2
S. Dak	859	116	50	925	921	−4
Utah	1, 200	149	100	1, 249	1, 250	+1
Vt	676	79	60	695	695	0
Va	5, 303	632	217	5, 718	5, 731	+13

*(1)=Total on register as of Dec. 31, 1965.
(2)=Additions during 1966.
(3)=Removals during 1966.
(4)=(1)+(2)−(3)=Expected total on register as of Dec. 31, 1966.
(5)=Actual total on register as of Dec. 31, 1966 (from State's 1966 punched cards).
(6)=Difference between expected total and actual total=(5)−(4).

TABLE 2.—*Register Accuracy Between December 31, 1966 and December 31, 1967*

MRA State	Total on register as of Dec. 31, 1966 (1)*	Additions during 1967 (2)	Removals during 1967 (3)	Expected total on register as of Dec. 31, 1967 (4)	Actual total on register as of Dec. 31, 1967 (5)	Difference between expected total and actual total (6)
Conn	3, 402	429	311	3, 520	3, 523	+3
Ga	5, 055	552	293	5, 314	5, 324	+10
Kans	3, 299	387	654	3, 032	3, 031	−1
La	6, 110	631	434	6, 307	6, 307	0
Mass	9, 741	1, 044	608	10, 177	10, 183	+6
N.H	1, 048	138	95	1, 091	1, 099	+8
N.J	7, 295	338	205	7, 428	7, 438	+10
N. Mex	2, 532	79	9	2, 602	2, 604	+2
N.C	10, 383	1, 180	1, 019	10, 544	10, 544	0
Oreg	2, 489	375	287	2, 577	2, 577	0
R.I	1, 086	133	72	1, 147	1, 146	−1
S. Dak	921	68	78	911	911	0
Utah	1, 250	155	105	1, 300	1, 301	+1
Vt	695	94	70	719	719	0
Va	5, 731	631	1, 361	5, 001	5, 007	+6

*(1)=Total on register as of Dec. 31, 1966.
(2)=Additions during 1967.
(3)=Removals during 1967.
(4)=(1)+(2)−(3)=Expected total on register as of Dec. 31, 1967.
(5)=Actual total on register as of Dec. 31, 1967 (from States 1967 punched cards).
(6)=Difference between expected total and actual total=(5)−(4).

CAUSES of BLINDNESS in 4,965 PERSONS WHOM 14 STATES ADDED to THEIR MRA REGISTERS in 1966

A STAFF PAPER [1]

THE 14 STATES [2] that were in the Model Reporting Area (MRA) for Blindness on January 1, 1966, added a total of 5,684 persons to their MRA registers in 1966, and had 55,982 persons in their MRA registers in December 31, 1966.

The total additions of 5,684 persons was comprised of 4,965 whose eyes were examined by ophthalmologists or eye-ear-nose-and-throat (EENT) specialists, 123 whose eyes were examined by other M.D.'s, 383 whose eyes were examined by nonmedical and unknown disciplines, and 213 readditions to these registers.

This paper is concerned only with the 4,965 additions, whose eyes were examined by ophthalmologists or EENT specialists. It analyzes the blinding affections and etiologies which these eye specialists recorded in their eye examination reports for these 4,965 additions.

Since age was not known for 168 of the 4,965 additions, a total of only 4,797 additions are distributed by age groups in Figures 3 through 9 of this paper.

From MRA's beginning in 1962 through 1964 each MRA State classified blinding affections with a three-digit code and their etiologies with a four-digit code. These two codes combined, therefore, constitute a seven-digit code.[3] Beginning with 1963, the National Institute of Neurological Diseases and Blindness (NINDB) has cumulated State data to

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[1] Helen B. Moorhead (Mrs.), Medical Record Librarian, Section on Blindness Statistics, Office of Biometry, NINDS, presented this paper to this MRA Conference on May 23, 1968. She and Russell R. Widney, M.D., the Section's Ophthalmologist, were the principal analysts for this study. They were assisted by Cecelia B. Clark, a Statistical Assistant in the Section, and were supervised by Paul H. Anderson, Ph. D., its Acting Head. Advice on charting and statistical concepts was obtained from James E. Johnson, Programer and Richard L. Moody, Systems Analyst, both from the Section on Systems Design and Data Processing, Office of Biometry.

[2] Connecticut, Kansas, Louisiana, Masachusetts, New Hampshire, New Jersey, New Mexico, North Carolina, Oregon, Rhode Island, South Dakota, Utah, Vermont, and Virginia.

[3] *Standard Classification of Causes of Severe Vision Impairment and Blindness,* National Society for the Prevention of Blindness, Inc., 79 Madison Ave., New York, N.Y.

produce statistics on causes of blindness in additions to MRA registers in each year.

MRA initiated a program in 1965 to improve and control the quality of the coding of affections and etiologies by MRA member States. In this program the NINDB reviewed the affection and etiology codes that the MRA member States had assigned to additions to their MRA registers in 1965.

Upon reviewing a sample of coded eye reports for persons added to MRA registers in 1965, the NINDB learned that the coding was not comparable between States because they classified identical eye reports differently, coded different primary causes in identical eye reports, gave the same code to different causes, or gave different codes to the same cause.

NINDB combined the seven-digit cause codes for the additions to MRA registers in 1965 into 18 clinical conditions and presented the results at MRA's Conference held in 1967.

The seven-digit cause codes were combined into larger groups because the seven-digit coding system extends beyond the limits of medical knowledge in general, assignment of a code often implies a greater knowledge of an individual case than can be assumed from the eye reports, assignment of an etiology code often is arbitrary and blindness causes should be reported back to ophthalmologists in a simpler code which is more meaningful to them.[4]

It should be noted that affections and etiologies are coded only in eye examination reports from ophthalmologists or EENT specialists. The states had coded the affections and etiologies reported for 4,965 additions to their registers in 1966. MRA member States sent eye examination reports to NINDB for 4,866 of these additions. NINDB reviewed the affection and etiology codes the states had assigned in all of these reports and accepted the codes the States had reported for 99 persons for whom they had not forwarded eye examination reports.

NINDB reviewed the affection and etiology codes the states had assigned to the 1966 additions to their MRA registers, giving special attention to code assignments if the primary cause of blindness was not clearly evident, diagnostic terms were not listed in the coding manual, or the eye examiner stated that the cause of blindness was probable, possible, or suspected.

NINDB combined the 4,965 eye-examination reports, which had been coded with 305 different seven-digit codes, into 16 clinical cause categories.

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[4] Widner, Russell R., M.D., "Reclassification of the 1965 Cause-of-Blindness Data." *Proceedings Sixth Annual Conference of the Model Reporting Area for Blindness Statistics 1967.* U.S. Department of Health, Education, and Welfare, National Institutes of Health, Bethesda, Md.

Figure 1 lists the 16 clinical causes in their frequency order, with most frequent at top. Macular degeneration, the most frequent, blinded 20 percent of the 4,965 additions, and cataract, the second, blinded 17 percent. Glaucoma, diabetic retinopathy, and congenital defects, which were third, fourth, and fifth respectively, blinded 13, 12, and 9 percent. Abiotrophic chorioretinal disease and degenerative myopia, which was the sixth cause, blinded 6 percent. The seventh through 15th causes each affected less than 5 percent of additions. In decreasing frequency order, these causes are as follows:

Blindness Cause:	Percent of 4,965 additions
Optic nerve diseases	4
Retinal vascular diseases	3
Uveitis	3
Corneal diseases	2
Injury and poisoning	2
Retinal detachment	1
Other central nervous system diseases	1
Retrolental fibroplasia	1
Retinoblastoma	0. 2

The unclassified and unknown category, which represents 6 percent of additions, is shown last and not in frequency order because of its diversity.

Figure 2, which cumulates the 16 clinical causes in their diminishing frequency order starting with the most frequent at bottom, shows that the three most frequent causes combined affected half of the 4,965 additions, that the four most frequent ones affected 60 percent of them, that the first six affected over 75 percent, and consequently, that the remaining 10 causes affected less than 25 percent.

Figure 3 distributes 4,797 persons with known ages to age groups 0–20 years, 21–40, 41–60, and over 60. The over 60 age group had the largest number of persons, which was 59 percent of 4,797. The 41–60 age group, which was the second largest, had 21 percent of them. The 0–20 age group, the third largest, had 12 percent. The 21–40 age group, which was the smallest, had 8 percent. The 4,797 additions with known ages had an average age of 61.

Figure 4 discloses the average age as of 1966 of the persons that each cause blinded. Average age when blinded would be lower due to delayed registration of blinded persons. This figure shows that the 16 causes did not blind all age groups equally; that the average age was 72 or higher for macular degeneration, glaucoma, cataract, and retinal vascular diseases; that the average age was 67 for unclassified and unknown diseases, and 62 for retinal detachment; that the average age was 41–60 for six causes; that the average age was 40 for injuries and poisonings; that the average age for congenital defects and retrolental fibroplasia was 18; and that retinoblastoma had the lowest average age, which was 3.

Figure 5 illustrates further that persons with different causes were registered at different ages. It distributes four causes with different registration patterns by age at registration. These are: (1) Congenital defects, (2) macular degeneration, (3) diabetic retinopathy, and (4) abiotrophic chorioretinal disease and degenerative myopia.

Persons with congenital defects were registered, as expected, while young. Seventy percent of the 462 persons with known ages who were blinded by this cause were in the 0–20 age group, and registration decreased for each age group thereafter.

Macular degeneration shows an opposite pattern. Only 2 percent of the 928 persons with known ages whom this cause blinded were registered by age 20. Registration increased slightly in the next two age groups, and sharply in old persons. Ninety percent of these 928 additions were registered after age 60.

Like macular degeneration, diabetic retinopathy showed increasing registration with each age group; however, unlike macular degeneration, approximately half of the registrations for diabetic retinopathy occurred before age 61.

The fourth cause, abiotrophic chorioretinal disease and degenerative myopia, showed a different type pattern from the other three causes. Registrations did not increase with each successive age group, but occurred in significant numbers in all four age groups. There was only about 15 percent difference between the group with most registrations, 41–60, and the one with the least, 0–20.

Figures 4 and 5 disclose that blindness causes were not equally distributed by age of the blinded. Figures 6 through 9 show the four most frequent causes for persons over 60, 41–60, 21–40, and 0–20.

Figure 6 discloses that 2,818 additions, representing 59 percent of the 4,797 additions with known ages, were older than 60. It also reveals that macular degeneration was the most frequently reported cause for this age group, and that cataract, glaucoma, and diabetic retinopathy were second, third, and fourth respectively. These four clinical causes affected about 80 percent of persons in this age group. The most frequent causes in this age group also were the most frequent for all additions combined. as was shown in Figure 1.

The most frequent blindness causes in 992 additions in age group 41–60 are presented in Figure 7. Diabetic retinopathy, cataract, and glaucoma were the first, second, and third, respectively. Abiotrophic chorioretinal disease and degenerative myopia was fourth. These four causes affected about 58 percent of the persons in this age group.

Figure 8 identifies the most frequently reported causes for 400 additions in age group 21–40. Congenital defects and diabetic retinopathy were first and second respectively. Abiotrophic chorioretinal disease and degenerative myopia was third, and injury and poisoning was fourth.

These causes blinded 65 percent of the persons in this age category. Injury and poisoning was a leading cause of blindness only in this age group.

The most frequently reported causes in 587 additions in age group 0–20 are indicated in Figure 9. Congenital defects was first. Abiotrophic chorioretinal disease and degenerative myopia was second, and optic nerve diseases and retrolenthal fibroplasia were third and fourth, respectively. Congenital defects blinded 55 percent of the persons in this age group. It is the only age group in which a single cause blinded more than half the persons. These four leading causes blinded 80 percent of the total additions for this age group.

Figures 1 and 2 disclosed the frequency of 16 blindness causes in 4,965 additions to MRA registers in 1966. Figures 3 through 9 revealed how blindness causes were distributed by age groups in 4,797 of these additions which had known ages. These 16 causes were not necessarily distributed in the same way or even similarly in the 55,982 persons who were in the 14 MRA registers on December 31, 1966.

The additions to MRA registers in 1965 were distributed by NINDB to similar, but not identical categories and it was found that the frequency distributions for the 2 years were only roughly similar. The additions to MRA registers in 1962 through 1964 have not been distributed in this manner. The information for 1965 and 1966 additions to MRA registers does not provide a sufficient basis for predicting how the additions in 1967, or in any other year ahead, will be distributed to these 16 clinical causes.

Frequency of the Causes of Blindness In 4,965 Additions to MRA Registers in 1966

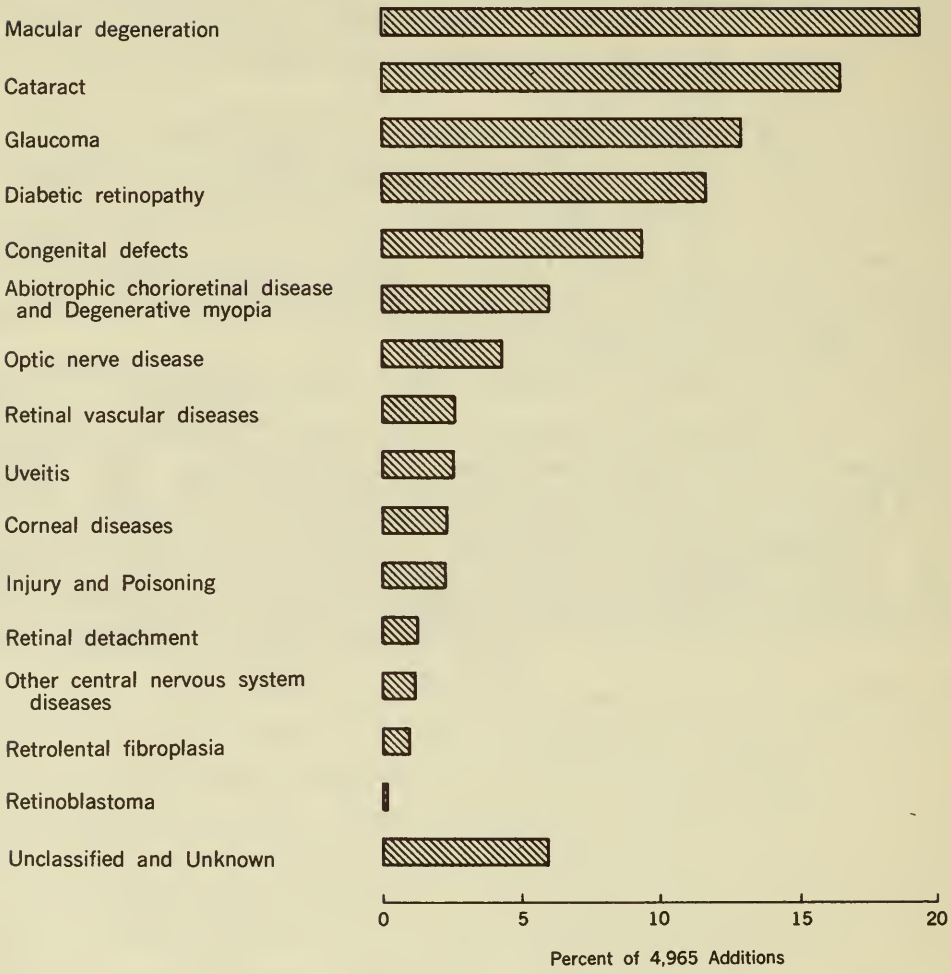

FIGURE 1

Cumulated Frequency of the Causes of Blindness In 4,965 Additions to MRA Registers in 1966

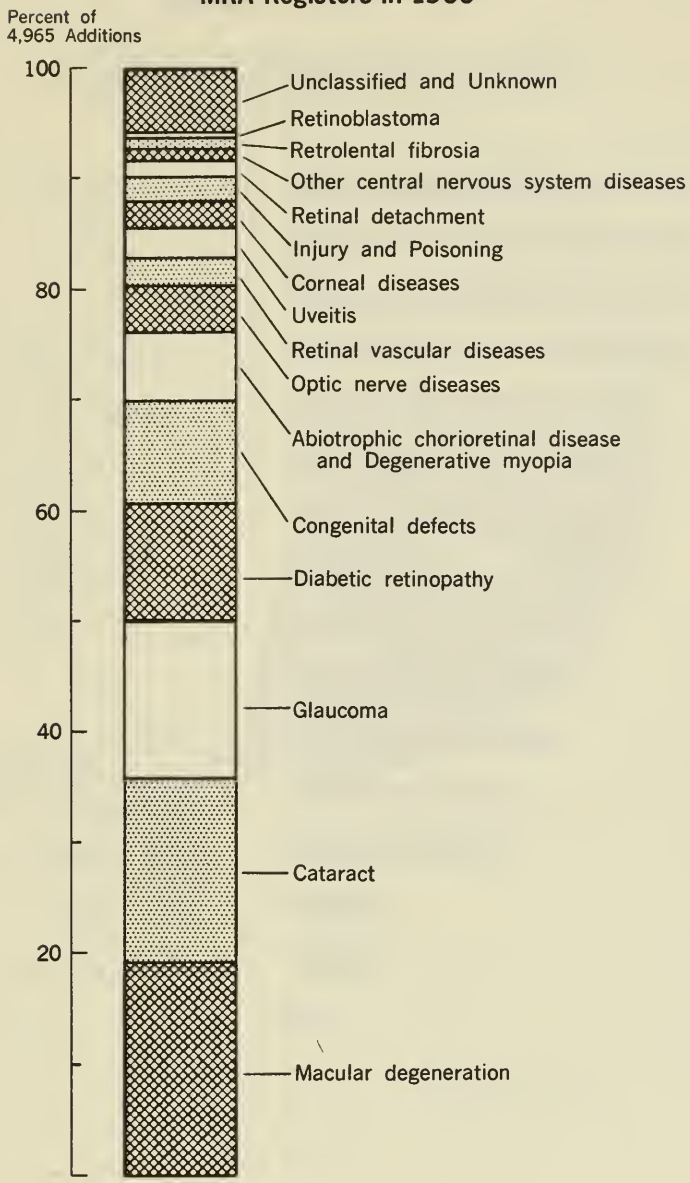

FIGURE 2

349-556 O—69——6

Frequency of Persons by Age Groups
In 4,797 Additions to MRA Registers
In 1966 With Known Ages

(The % figure for an age group is the number of persons in that age group as a % of 4,797)

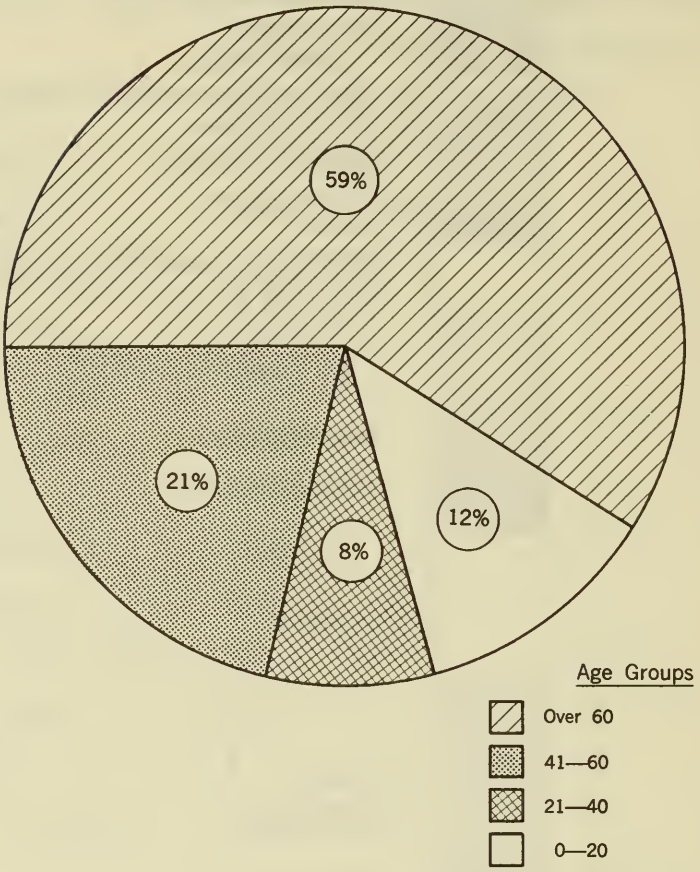

FIGURE 3

Average Age by Cause of Blindness In 4,797 Additions of Known Age To MRA Registers in 1966

(The average age of the persons blinded by a cause is reflected by the length of the bar and by the figure recorded in a circle at its left end.)

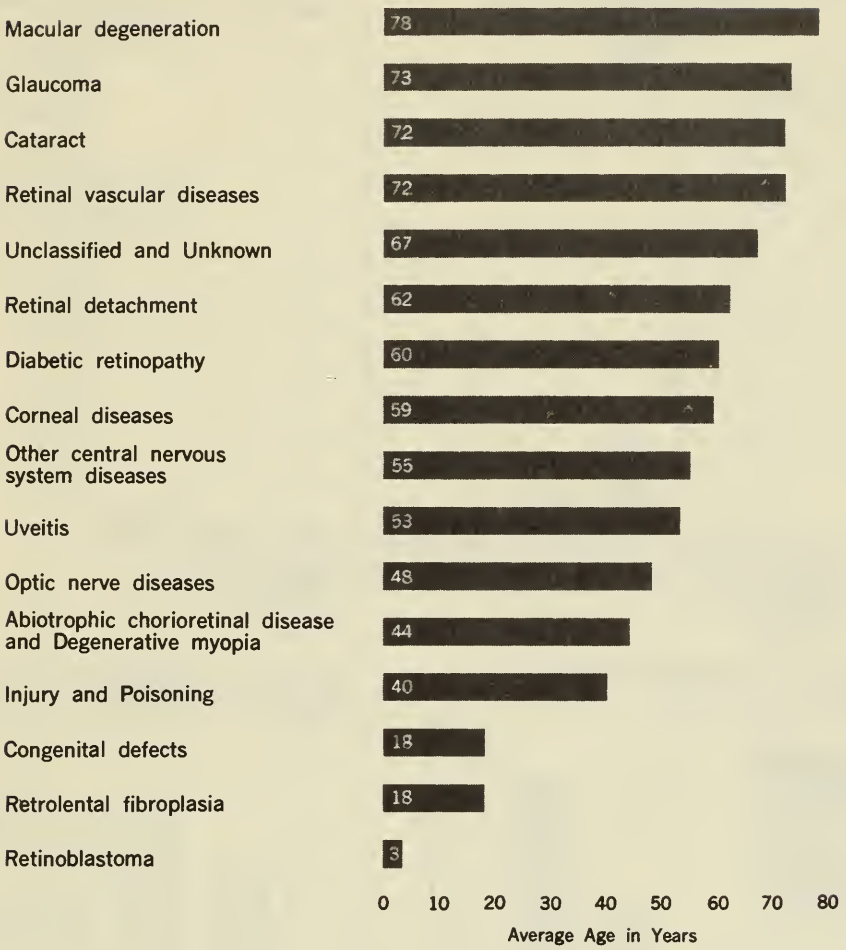

FIGURE 4

Frequency of Selected Causes of Blindness by Age Groups In Additions to MRA Registers In 1966

The number of additions shown in the title of each individual graph is the number of people with known ages who were blinded by the cause. It is not the total number blinded by that particular cause.

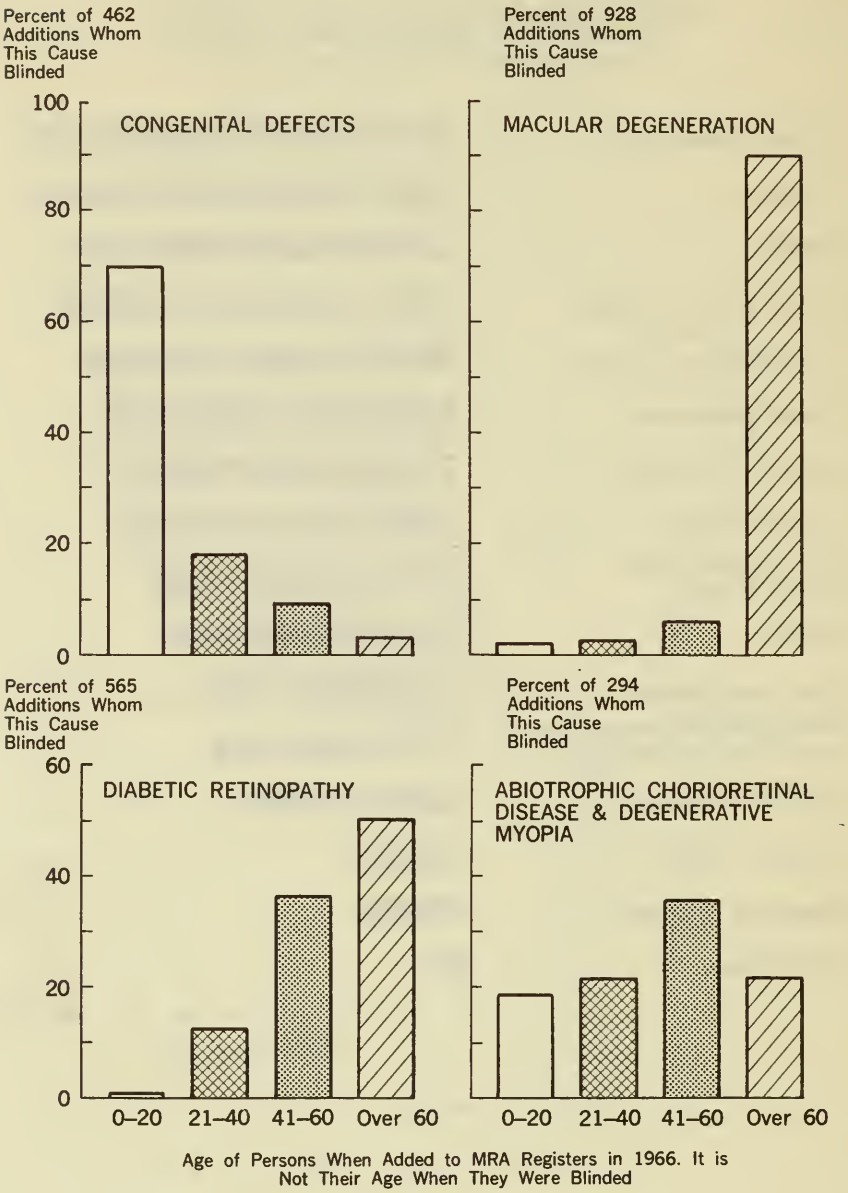

FIGURE 5

Most Frequent Causes of Blindness in 2,818 Additions to MRA Registers in 1966 Who Were Then in the Age Group Over 60

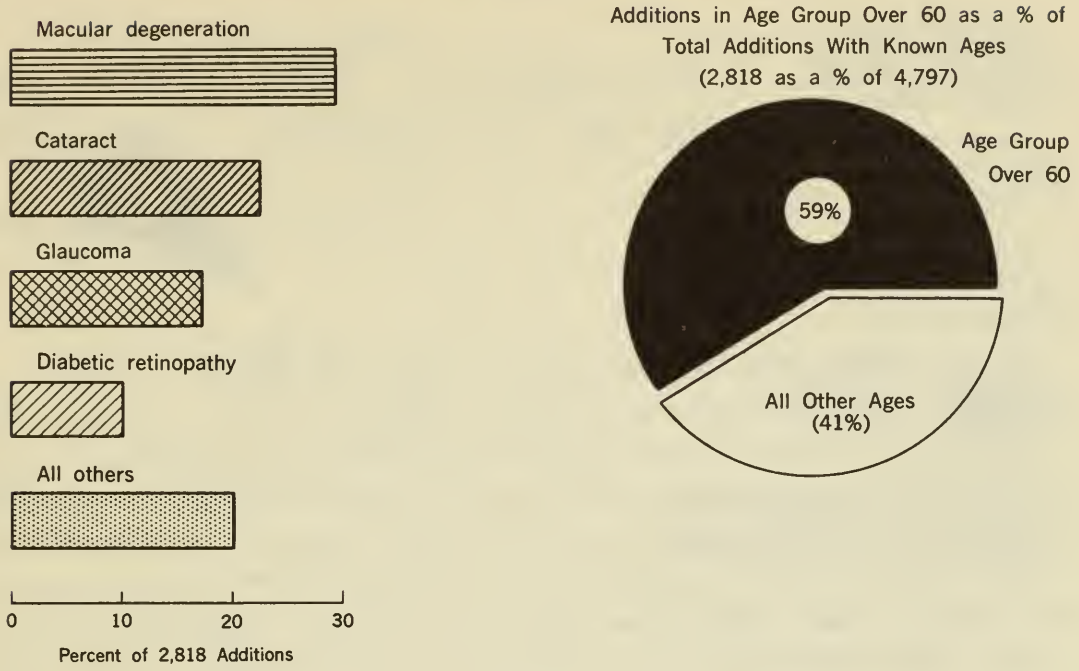

FIGURE 6

Most Frequent Causes of Blindness in 992 Additions to MRA Registers in 1966 Who Were Then in Age Group 41–60

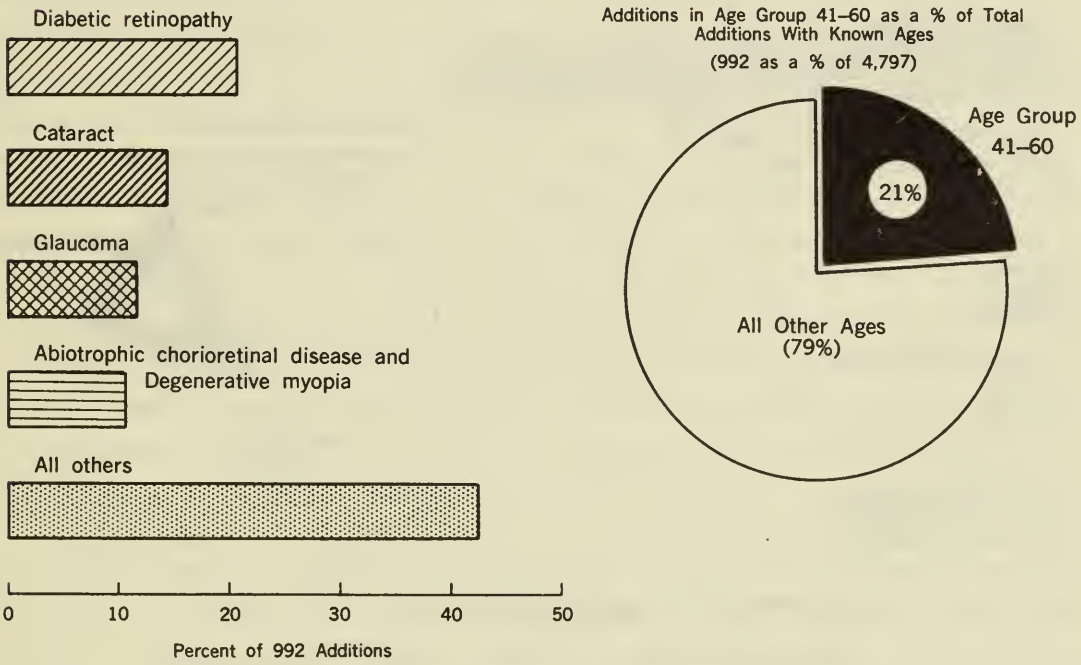

FIGURE 7

Most Frequent Causes of Blindness in 400 Additions to MRA Registers in 1966 Who Were Then in Age Group 21–40

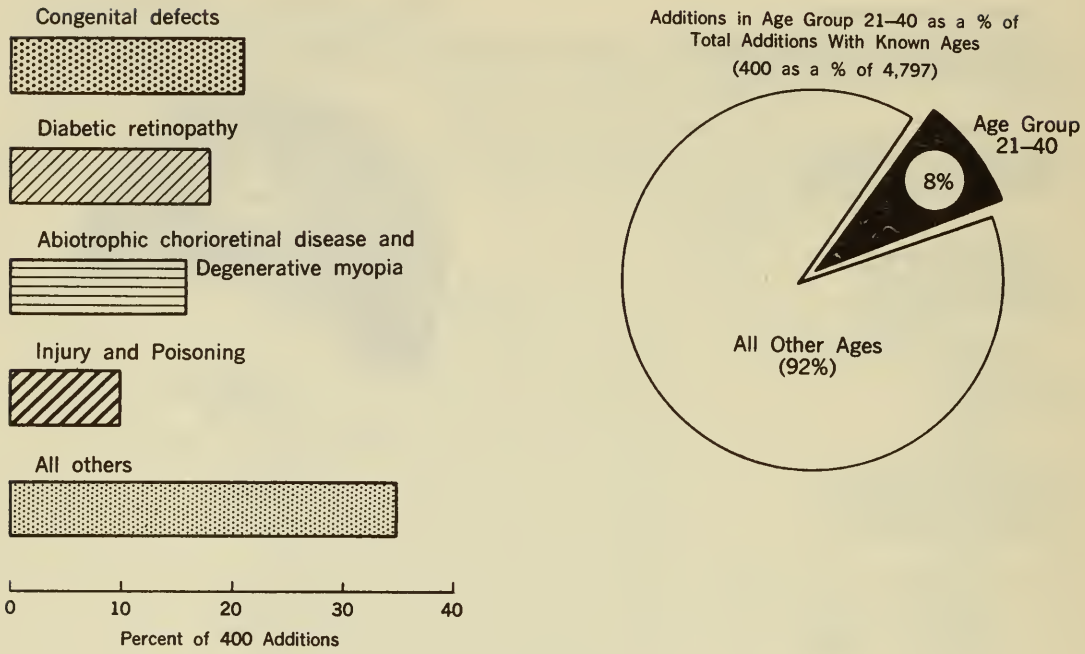

FIGURE 8

Most Frequent Causes of Blindness in 587 Additions to MRA Registers in 1966 Who Were Then in Age Group 0–20

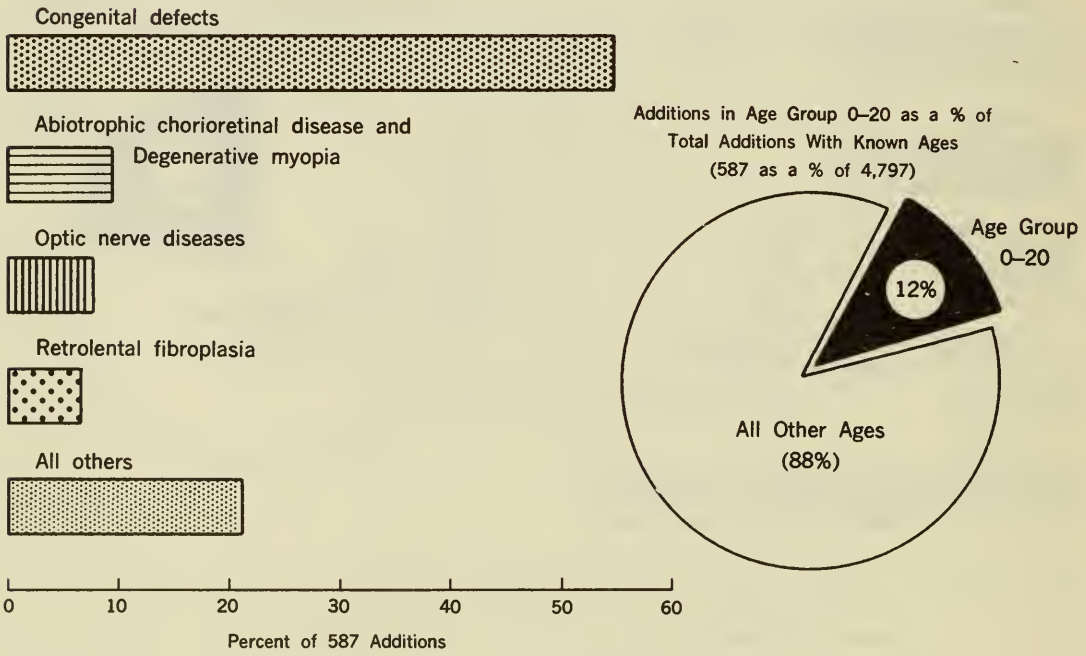

FIGURE 9

The ALLOCATION of FUNDS for PROVIDING SERVICES to the BLIND

GERALD ROSENTHAL Ph. D.[1]

A DISCUSSION of the allocation of funds for providing services to the blind may be approached from a number of dimensions. It is my purpose today to provide some general observations on the *process* of allocation. There are two levels on which such an issue can be discussed. One might be interested in allocating funds for blindness as opposed to other types of expenditures or for allocation of funds between blindness and similar types of disabilities. On the other hand, within the total allocation of funds for providing services to the blind, a number of allocative questions, equally relevant, can be approached. Issues relating to the nature of the services for which funds are to be allocated, the objectives of these services, and who the recipients of these services are to be all represent examples of allocative questions.

It is this latter set of allocative questions which will be discussed here. The observations I will make and the experience which I will relate reflect primarily the result of an analysis performed by the Organization for Social and Technical Innovation (OSTI) for the Rehabilitation Subcommittee of the National Institute of Neurological Diseases and Blindness. The study was directed at an overall examination of the system for providing services to the blind and the development of a number of analytic models for evaluating the implications of alternative criteria for allocation of funds. In the course of that exercise a number of ideas were developed which might be of some interest here today.

It must be emphasized that in order to allocate, one needs to develop criteria, or recipes, for making appropriate decisions. Since every service to the blind must serve some objective, the basic problem of allocation is to distribute the resources in such a manner as to maximally serve the overall objectives of blindness services as a whole.

This activity is made more difficult by the fact that at any moment in time, there are a number of separate, and often incompatible, objectives desired by individual decision makers. Each activity or service potentially makes a unique and different contribution to each group of recipients. Ideally, if there were only a single objective, one could compare each

[1] Associate Professor of Economics, Brandeis University and Senior Associate, Organization for Social and Technical Innovation (OSTI).

array of expenditures in terms of their expected contribution to the objective and select the best mix. In actual fact, there is no single objective and it is rare that such a simple-minded approach to allocation will yield a meaningful result.

Perhaps of more significance is the fact that there is no single decision maker who has the authority or responsibility to determine a single allocation of funds for providing services to the blind. Indeed, a number of independent decision makers behave in ways which are designed to serve the objectives which they deem to be important with the resources over which they have some control. The end result of this, however, may yield more consistency than would be expected at first glance.

As part of the OSTI analysis, an attempt was made to relate the distribution of services to the potential recipients of such services and to examine the allocations of services to recipients which would be most consistent with a number of alternative overall objectives for the system of blindness services as a whole.

For this purpose, the services were described in a few broad categories: support, both residential and income maintenance, vocational training, education, and instrumental services which includes psycho-social counseling, communications aids, etc. The services, as defined above, were related to groups of potential recipients defined in such a way so that different objectives might be feasible. The groups used were the aged, children who are blind only, multiply handicapped children, and those of working age divided into two age groups—a group 25 through 44 and the group 45 through 64.

Different objectives, of course, will shift the emphasis on certain types of services. Each of these services will make a different type of contribution to each of the groups described as potential recipients. For some groups, some services may not be relevant at all.

Before one can undertake the exercise which has been suggested here, it is necessary to acknowledge some real constraints on the choices available. First, it is hard to shrink or curtail certain activities already underway either due to the requirements of the bureaucracy or commitments to clients. Second, much of blindness services are provided by independent agencies or groups who are nonresponsive to stimuli for change unless such stimuli come from their own boards or, possibly, from those who are regarded as their relevant client population. Third, the services themselves are very fragmented, and the use of aggregate categories, such as instrumental services, may obscure considerably more than they illuminate. Fourth, the locus of certain commitments are pre-established. For example, the responsibility for educational activities falls on the State because of the nature of the locus of educational activities for the nonblind and will reflect the educational systems objectives as well as the business systems objectives.

All of the above noted constraints lead to the observation that there are no truly central allocative activities which can be undertaken. What must occur in reality is that the allocator or the overall decision maker must think in terms of filling the gaps and perhaps stimulating shifts in directions to make the actual allocation of funds more consistent with overall objectives.

It seems useful to take an alternative way of viewing the activities which occur in the blindness system. As part of the OSTI study an attempt was made to look at the current activities as they actually operate and to contrast the implicit objectives manifested in the observable behavior with the espoused objectives suggested to us by a number of those who are providers of services to the blind. What we asked was, what objectives are actually being served by the current system and the current allocation of funds for services to the blind.

As an initial step two assumptions were made. First, that all potential users of services for the blind would be encountered somehow by the system and second, that each service will be provided in a manner which is indicative of the best observable practice as a result of our examination of blindness services. Four basic objectives for the blindness system were examined:

1. To minimize the cost of services to the blind to the blindness system.
2. To minimize the cost of services to the blind to society as a whole.
3. To maximize economic independence of the blind.
4. To maximize social independence of the blind.

Each of these objectives is a point on a continuum. The exercise leads to the observation that, for the potentially trainable, vocational education or educational activities are undertaken up to the point where the expected returns offset the costs. With the first objective it is only the returns to the blindness system itself which are relevant. This means that one needs a higher probability of future employment for undertaking vocational activities than one would if one were evaluating the benefits of those economic activities to society as a whole as an offset to the cost of undertaking the activities. The objective of maximum economic functioning leads to a development of a set of services to the blind designed to enable every individual with *any* possibility whatever of achieving any degree of economic independence is an unrealistic objective, particularly the aged, considerable instrumental services would be provided in an effort to enable greater physical mobility, social adjustment, and greater potential for fruitful existence. It must be noted that this last objective was the goal stated by most people actually engaged in the process of providing blindness services.

The operational implications of each of these criteria were as follows: If cost minimization was the objective subject to the constraint that some-

thing was done with all the blind, then all of the aged got minimum support which was calculated both at $1,500 a year and at $3,000 a year. For others, you would spend up to the potential support cost for vocational and educational services. Instrumental services in general got short-shrift unless developed as part of vocational services. For maximum human functioning, the emphasis shifts considerably. If maximum economic independence is desired then any expenditure is justified to assist any individual in becoming employed. If the budget is limited, maximizing might lead to a set of activities where the system appears to be cost-minimizing although it truly wishes to serve the objective of maximum human independence. With respect to a number of individual blindness agencies, the fiscal constraints are not likely to generate the absolute necessity for constraining client population as narrowly as often now occurs.

A few other aspects of allocation of funds for the services to the blind might be of interest. It must be noted that certain activities require a considerable period of time before any results which are susceptible of evaluation occur. This means that if one is primarily interested in serving short-run objectives, these activities are not likely to be undertaken. An example is the relative lack of attention paid to various kinds of prevention on the grounds that such activities (other than glaucoma screening) are unlikely to make a significant dent on the potential recipient population for services. Another consideration which frequently will affect the ability to allocate funds in an optimal manner is the problem of scale. Some activities must be carried on in large programs or not at all if any end results are to be observed. For example, vocational education programs without followup employment services are likely to show considerably less in terms of end results than would a much larger program which developed the employment base to absorb the vocationally trained individuals. Another example, not from the blindness field, is the Head-Start program. There are indications that such a program without systematic followup might lead in the long run to no net impact on the problems for which the program was developed.

It must be emphasized again that the process of allocating resources requires that one be aware that the appropriate choice follows from one's view of the objectives of the expenditure and the period within which the returns from such expenditures are expected to manifest themselves. Any revision of objectives is likely to require adaptation in the form of a change in the allocation of funds from that which was previously considered optimal.

As I noted in my opening comments, it is impossible for anyone to come and provide a recipe as to how resources ought to be allocated. The purpose of this discussion was to share with you some observations with regard to the allocation of resources for providing services to the blind. The constraints on the achievement of an effective allocation are pri-

marily the fragmentation of decisionmaking and the diversity of the potential recipients of services. As things stand today, there is no central allocation, there is no planning, there is no optimal budgetary distribution and there is considerable evidence that the current use of resources may not make a maximum contribution towards enabling the blind to achieve a greater level of human functioning or participation in society. That is, of course, the ultimate challenge. To the extent that our discussion can contribute a bit to an awareness of the magnitude of that issue and to suggest some directions for movement, I for one will consider it a fruitful exercise.

STIMULATING EYE EXAMINERS to REPORT BLINDNESS to a STATE REGISTER

KARL W. STOCK, M.D.[1]

MY COMMENTS will be related to stimulating the doctor group to report blindness to the State register.

Recognizing this is the group who should be reporting, it follows that every effort should be made to encourage full participation. Your program of services to persons with visual impairment should enhance in effectiveness, in completeness of services and in acceptance by the general public if you have the physicians with you.

Let us first consider some of the probable reasons why doctors fail to send in a report on a patient who has blindness.

Some doctors, I am certain, have not been requested to do so and many more have forgotten that a blindness register exists. Reporting is time consuming and now seems more so with the multiplicity of forms demanded by the government programs. Frequently doctors do not understand the importance of blindness reporting. Others do not accept the importance and look upon this as just another request from a government agency. Another factor and an important one is medical ethics. Doctors are concerned with releasing medical data unless requested to do so by the patient as the problem of confidentiality of medical data has never been resolved. We should also recognize the importance of the doctor's personal feelings which enter into the reasons already mentioned but in addition there is the doctor who is not in accord with your program. He very likely is one who has not seen or felt the benefits of services to his patient. Nevertheless, he appears not interested so you find it difficult to approach this doctor and tend to stay away from him.

Here are some suggestions I have for stimulating the doctor's interest and cooperation.

First, know your eye physicians, involve them in program planning, help them to feel the program to serve persons with a visual impairment is their program, too. Help them to feel the gathering of statistical data on characteristics of the blind population is as important to them as to

[1] Dr. Stock, State Supervising Ophthalmologist for Kansas, prepared this paper for presentation to this conference. Miss Marguerite Blase, Medical Social Work Consultant, Kansas Division of Services for the Blind, presented the paper for him since he could not attend due to illness.

you. An end result of the statistical study is or should be of benefit to his patient—don't stay away from the doctor.

More specifically, personal contacts with the physician cannot be overemphasized. Work with the physician in serving your client and let him know what is happening to his patient. Acquaint the physician with what you can do to help the patient with adjustment and other problems related to blindness. At the same time get him interested in the total program. Once a relationship is established with the physician, you will have no problem with securing his full interest and cooperation. This has been our experience in Kansas but we have not gone far enough with enlisting the physician's help to all segments of our program. The eye physicians have given full cooperation, evidenced much interest and a feeling of pride with respect to the Kansas program of direct medical services to prevent blindness and/or restoration of eyesight. Some of our eye physicians refer to this particular program as "our" program—meaning mine and yours. Here, we have involved the physician and in the various administrative aspects from the very beginning of the program.

Medical advisory committees can be of great help if the committee is kept active and interested. We have such a committee in Kansas and plan to make the matter of blindness reporting its concern as well as ours and work together in implementing more complete reporting. We have found these eye physicians interested in helping.

Respect for the confidential nature of the physician's report is of great importance. If the report is given you for statistical purposes only, handle it this way. Do not go to his patient as one in need of services, though he may well be in need. Remember the doctor reported for statistical purposes only. However, a well informed doctor can consider the availability of services with his patient and suggest that an application be made or agree to ask the agency representative to call on the patient. Make certain the doctors are well informed of your service program and that they keep informed. You will in this way not only reach more persons but you can be more certain that your blindness register contains the majority of the blind population in your State. Also, if the report is given you in connection with a person's request for service, confidentiality of the information should likewise be respected. Physicians will share their records more readily if they know how the information is to be used and if you continue to demonstrate that you recognize the medical data as confidential.

Doctors are busy and often forget to report unless his patient requests that he do so. Periodic reminders to the doctors to encourage reporting can help. As one Kansas ophthalmologist says—"I have your letter in regard to means of stimulating reporting of blindness. Like many others I am sure, I have been quite remiss in reporting such cases. I think the most effective step which could be taken would be regular reminders to all doctors concerned, say monthly or quarterly, that they should report

all cases of blindness. This could take the shape of a form to be filled out and returned even if it was negative."

"With this periodic reminder I know that I personally would be much more likely to maintain a register."

The doctor's office staff are important people. The responsibility of preparing reports often falls to this staff—so they are key people in blindness reporting or at least in instigating the report. These people should know you and understand the importance of reporting to the State register as well as referring patients to you or advising the patient on the available services.

Simplify reporting as much as possible, especially where reporting is to the blindness register only. One of our physicians has suggested a small form such as this:

Name _____ age _____
Address _____

	Vision with glasses	Vision without glasses
R	_____	_____
L	_____	_____
Onset (age)	R _____	L _____
Diagnosis	R _____	L _____
Etiology	R _____	L _____

A telephone call to the doctor's office will get you any additional data needed.

Optometrists see many blind persons and should be involved in and encouraged to report using similar methods as suggested in stimulating reports from the eye physician. How you would get the necessary medical data, and you may not be able to in some instances, would be a matter to work out with the optometric and medical groups.

Last but not least, the use you make of the blindness register and keeping the doctor informed on what comes out of a statistical study will tend to develop interest. The doctor can then see and feel the value of gathering and registering certain data on characteristics of the blind population. I do not have in mind here a once a year report on register tabulations. This is fine but we need to do more studies on causes of blindness in your communities, studies showing where the blind people are living, urban or rural, studies showing the employment of blind persons in your State, etc., should stimulate much interest.

In summary, know your doctors, be sure they know you. This requires a consistent contact. Work out your problems with the doctor group. Ask them to consult with you on program matters. Again, don't stay away from your doctors.

STIMULATION of BLINDNESS REPORTING

JOHN F. MUNGOVAN [1]

THE REPORTING of blindness for the purpose of gathering statistics on the incidence and prevalence of blindness raises a great number of questions, many of which have no simple answer. To what extent is the reporting complete is the most obvious question. This query raises the most fundamental question of all. What constitutes blindness? How do we define blindness? The Model Reporting Area certainly has done much to standardize reporting by limiting the definition of blindness to the widely used 20/200—10 percent radius, one, but even within this definition, the functioning of the individual influences the decision on reporting.

Without doubt, many of the persons listed on our Register of the blind are not known by their friends, their neighbors, or even their doctors as blind persons. There is a current trend for agencies serving the blind to change their names from the "Commission for the Blind" to the "Commission for the Blind and Visually Handicapped." I understand that the reasons for the change in name are many. One important reason for such a change however, is the very practical one that many "legally blind" persons are not generally considered to be blind. Visually handicapped, or partially blind or even partially sighted, is a more descriptive term than "blind". There is an emotional overtone to the word "blind"—not so much in official State agencies as in small voluntary, charitable groups. I know a number of small voluntary groups organized to help the blind who are so emotionally involved with the concept of blindness that the members are extremely uncomfortable in the presence of blind persons. They constantly refer to the blind persons as "our visually handicapped friends." You can see, therefore, that there are many practical as well as emotional problems in developing a definition of a blind person.

A few years back in the Massachusetts Commission for the Blind, we had read about State Vocational Rehabilitation Agencies who had placed rather significant numbers of blind persons in public schools as classroom teachers. We were meeting with little success in our State Vocational Rehabilitation program in public school teacher placement of blind persons. Private schools, colleges and universities were receptive to the employment of blind teachers, but not so public schools in Massachusetts.

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[1] Commissioner, Massachusetts Commission for the Blind.

We decided we would try to locate blind public school teachers in one State which had frequently reported successful placement of blind persons in public schools. We wanted to ask the blind person how he obtained his job and how he functioned on the job so that we might better be able to counsel blind people in Massachusetts who were interested in obtaining public school teaching jobs.

In order to locate the blind teachers, we wrote to the superintendent of schools in each city or town which had been reported as employing blind teachers. What do you think our inquiry revealed? Every school department we wrote to sent back a reply saying we have no blind persons employed as teachers in this system. After we recovered from the surprise at these answers, we came to the conclusion that, in all probability, all of the persons placed had partial vision which eliminated many of the problems faced by those who function without vision. We suspect that the employers, families and the pupils did not consider these teachers to be blind. It seems to me that this especially demonstrates the difficulty almost everyone has in classifying partially sighted persons as blind within the 20/200 definition of blindness.

It is difficult for most persons in our society to define blindness without some consideration of the loss of social, educational or economic functioning in the blind person.

It seems, therefore, that notwithstanding the mandatory reporting laws, the fact that an individual is blind and, therefore, should be reported to the Commission for the Blind for registration, is dependent upon the attitude of the reporter. His primary concern is the well-being of his patient. Many will report blindness because the reporter is conscious of the law and legal considerations in general; others will be less concerned about the law but will be interested in how the patient can be helped to live as a blind person. Thus, the kind and quality of services available to blind persons has an effect on reporting.

Assuming that adequate services are available, we are then confronted with a communication problem. How can the availability of a variety of services be made known to blind persons, their friends and families, and the reporter? Since I am not an expert in the field of communications, I shall simply describe some of the avenues we in Massachusetts have employed to stimulate the reporting of blindness.

In our general information pamphlets, we briefly describe the services of the Commission and we also quote the mandatory reporting law. This law contains the definition of blindness. We publish an Annual Report which contains information on the incidence and prevalence of blindness, as well as measures of services rendered. This is not an elaborate professional publication, but we do distribute it to all principal social agencies, university libraries, and public libraries in the State.

Of course, a great inducement to report is the tax exemptions. We have

the Federal income tax exemption, a State income tax exemption, and a real estate tax exemption.

One important consideration which influences the reporter is that we keep his report confidential. We have a space on the mandatory reporting form so that the doctor can advise us not to contact the patient, if he thinks that this is advisable. We honor the doctor's suggestion by marking all of our records "DO NOT CONTACT" with a large black stamp and we keep such addressograph plates in a drawer so that when we take an annual census by mail, we do not send the letter to the "DO NOT CONTACT" registrants. When the registrant directly contacts the Commission, after having been reported as a "DO NOT CONTACT" registrant, his name is removed from this category.

Medical social work staffs of hospitals influence the reporting. We have almost daily contact with some of the large hospitals and, in addition, our medical social worker visits the social service staffs of hospitals in the State to keep them abreast of our services. Our staff, counsellors, social workers and home teachers regularly give talks to student nursing groups at Boston College, Boston University School of Nursing and the nurses training schools affiliated with hospitals.

Because we are in a city saturated with schools and colleges, we have contacts with a large number of students who have been assigned the task of writing a report or participating in a study project on blindness. These students are interviewed by a senior member of the Commission staff and are provided an information kit when they call.

We also are able to use the statistical data we accumulate to supply information to doctors who are preparing speeches or papers. We meet with residents in ophthalmology to inform them of services for the blind and occasionally provide information about how to procure our services at hospital rounds.

We have similar articles published in medical and optometric journals which call attention to the reporting law.

We circulate the Annual Report of the Model Reporting Area among members of the medical profession.

I write a column in "LISTEN," a bimonthly newspaper published by the Catholic Guild for All the Blind. This paper has a wide circulation in the State and serves as a reminder that blindness should be reported.

We acknowledge the receipt of every eye report from a physician or an optometrist. The variety of services available makes the reporting of blindness valuable to the blinded person.

The Talking Book program is a great help to blinded persons and most reporters are familiar with this service.

One-fare travel concessions, both interstate and intrastate, are considered to be of great value to some blinded persons.

The Rehabilitation Center facilities managed by the Catholic Guild

for All the Blind are readily appreciated by the medical profession. The Commission pays tuition for blind persons in these centers; these rehabilitation centers are St. Paul's for young and middle-aged persons and St. Raphael's for aging persons. Frequently our registrants come to us because the doctor refers the person for rehabilitation center training.

To sum up then: I have tried to indicate that reporting of blindness depends upon, first providing a wide range of services to blind persons, second, telling everybody possible that these services are available and, thirdly, frequently reminding the reporting sources that reporting of blindness is mandatory, is desirable and will result in better services to the blinded person.

STUDY of INFANTS and YOUNG CHILDREN with VISUAL PROBLEMS

(A preliminary report)

ELIZABETH M. HATFIELD, M.P.H.[1]

THIS PAPER discusses progress, preliminary results, and problems encountered in the study of infants and young children with visual problems initiated by the National Society for the Prevention of Blindness in October 1967.

Since the early 1930's, the National Society has conducted a series of studies of the causes of blindness in children of school age to obtain current information as well as trend data for program planning. The last such study was for the 1958–1959 school year.

In planning for another study of school children, we gave consideration to the possibility of a study of the preschool age group. Studies of the school age blind, done rather frequently, have generally provided us with all the information needed on the causes of blindness in young children. However, with a lapse of nearly 10 years in these studies, information on young children is not as current as desirable.

There have been reports that the number of preschool age blind is increasing and that other causes are replacing retrolental fibroplasia (RLF), which has been practically eliminated. We were also interested in knowing how many children are blind due to rubella. Therefore the preschool age group seemed more imperative for study at this time.

Studies of preschool age children are difficult because those with visual impairments are not well reported and special services are not generally available. Children with visual problems are often not reported until school age. However, emphasis by the National Society on early detection through the preschool vision screening program may change this.

A study of preschool age blind children in 1950 was prompted by continuing reports of a previously unknown ocular condition among infants which was causing blindness. This was RLF. Although services for preschool visually handicapped were limited, data were collected on 2,809 children from 33 agencies in 23 States and the District of Columbia. Since almost 50 percent of the children in the study were blind due to RLF, the National Society supported research to determine the cause of

[1] Consultant in Statistics, National Society for the Prevention of Blindness, Inc.

the disease. Unfortunately before the cause was discovered and controls were instituted some 12,000 children were blind due to RLF.

The specific objectives of this study of children under 7 years of age are: (1) to learn whether any major changes have occurred in the causes of blindness since 1950, (2) to learn what causes now present a significant threat to young children, and (3) to determine whether the incidence of blindness for this group is increasing, decreasing, or remaining stable.

There are a number of variables affecting incidence in this age group which must be considered. The sheer increase in the size of the population under 7 years of age will result in an increase in the number of blind without any change in rate. An expansion of services to this age group in recent years will result in more children with vision problems being known. Through comparison of the results with those of the previous study and with data from the last study of school age children, we hope to make some inferences concerning trends in overall incidence as well as specific causes.

The information from this study should be of value to researchers, those planning prevention of blindness programs, and those working with the visually handicapped. The results will provide guidelines for needed research and will be helpful in anticipating future needs and facilities for these children.

The procedure for this study is similar to that employed in 1950. Participation by agencies providing services to this age group is voluntary. Sampling procedures are not feasible, since neither reporting procedures nor services are uniform throughout the country. Although the study population may not be representative of all visually impaired preschool youngsters we feel that the results will give an indication of the nature and extent of vision impairments in this age group.

Registers of preschool visually impaired are either nonexistent or incomplete in most States. The studies of school children have shown that blind children are frequently not reported until they are of school age. With increased emphasis on reporting in Model Reporting Area States and continued expansion of services for the preschool group, underreporting may be reduced.

Many agencies providing services to preschool blind cooperated in the 1950 study and could be expected to participate in the current study. It seemed reasonable to assume that these agencies would have some type of eye examination report for each child being served and that they would have a reasonably complete count. They were asked to supply case records for all partially seeing or legally blind children under 7 years of age as of December 31, 1966.

All State agencies for the blind were surveyed initially. If there was no central register or services were not provided to this age group, other State and/or local agencies were contacted.

Participation varies from State to State. Two or more agencies in several States are providing records for all known visually impaired children. In one State, local school systems with special services for the visually handicapped and the residential school for the blind are providing the necessary data.

Cooperation and interest in the study are remarkably good. As a result of all contacts made, 60 agencies are expected to participate. These are as follows:

	Number of States
Official State Agencies for the Blind	20
State Schools for the Blind	24
State Departments of Education	6
Voluntary Local Agencies for the Blind	9
Local public school systems	1 (43 districts)

Although, a deadline of February 1, 1968, was set for the receipt of records, extensions have been granted to enable participation of some agencies. To date records have been received from 42 agencies.

The study population will consist of children with visual impairments severe enough to classify them as partially seeing or legally blind who were under 7 years of age as of December 31, 1965. The partially seeing have a visual acuity for distance greater than 20/200 but not greater than 20/70 in the better eye with correction while the legally blind have a visual acuity for distance of 20/200 or less in the better eye with correction or a field restricted to 20° or less in the widest diameter.

Inadvertently, records on all children born between January 1, 1959 and December 31, 1966, were requested. Information on 1967 births was not asked for, since it was assumed that these would be grossly underreported as of February 1, 1968. This is apparently also true of 1966 births. The study will be confined, as originally intended, to those under 7 years of age, and 1966 rather than 1959 births will be excluded.

For the purpose of the study a copy of the eye examination report on each eligible child was requested. Although we were prepared to furnish each agency eye examination report forms (a modification of the NSPB "Eye Report for Children With Visual Problems") we preferred photocopies of the agency's case record materials. This would eliminate the need for interpretation of the information—particularly diagnostic—in transferring data from one record to the other and also the chance for omission of pertinent data or for transcribing errors. A variety of case record forms is being received, but interpretation is being done centrally and uniformly.

Information was requested for each child on age, sex, onset of blindness *each eye*, visual acuity or its approximation *each eye*, diagnosis or cause of vision impairment, family history, prognosis, treatment, and other handicaps. Since a standard reporting form was not used by all agencies some items are not reported. In the analysis only records on

which age, visual acuity, and cause data are reasonably complete will be included.

The records are being processed, and we hope to complete our analysis of the findings and have a report ready by the end of the year. It will be published in the National Society's quarterly journal, *The Sight-Saving Review.*

Some preliminary results are available at this time.

To date 42 agencies have supplied 3,745 case records. Of these 811 are ineligible for the study because of age, vision, or duplication. This leaves a total of 2,934 children born in the years 1959 through 1965 available for study. A large proportion of the ineligible records are from one agency. Vision measurements are not given for these children, and they appear to be remedial eye care clinic cases with only minor eye problems, such as refractive errors or strabismus. Some may have a serious vision impairment, but this cannot be determined from the data available.

The entire country appears to be well represented. Reports have been received from 31 States, and each geographic region is represented by two or more States. Records for more than 100 children have been received from all except three regions. With the receipt of additional records representation should improve.

The records have been divided into three broad groups on the basis of the amount of remaining vision: legally blind (63%), cannot classify (22%), and partially seeing (6%). No decision has been made concerning the remainder (9%). The "cannot classify" group will be subdivided into "assumed legally blind" and "other."

Classification of these children according to visual acuity has been difficult because exact measurements for infants and very young children are frequently impossible to determine. Many of the children apparently have a vision problem and have been accepted by a blindness agency for services. However, whether they are "legally blind" or not may be only a guess. The examiner frequently reports that the child "sees light" and/or "follows light," "sees objects," or "sees hand movements." Although the child may see more, the amount cannot be measured. For the study such vision is classified as "light perception" or "motion perception."

It is of interest that some children who apparently saw very little when initially reported were found to have developed useful and measurable vision on subsequent examinations and thus could be accurately classified.

Some cases for which no report on vision is given will be placed in the "cannot classify, assumed legally blind" category. If a detailed description of the eye and the nature of the affection is available, it is often possible to infer that the child is legally blind. Also included in this cate-

gory will be cases designated by the reporting agency as "blind" unless the eye affection is minor in nature or only one eye is seriously involved. Since it is not always possible to make a reasonable judgment concerning vision from the diagnosis, many cases will fall in the "cannot classify, other" category.

It can be assumed that among young children the severely visually impaired or those with obvious defects are most likely to be reported early. Therefore, the most precise vision category probably will be the "totally blind," with the "light perception" and "motion perception" categories grossly overstated.

Most of the study cases are in the older ages as expected. The "legally blind" and "cannot classify" groups combined are distributed as follows: 25 percent are 6 years of age, 50 percent are 3–5 years of age, 19 percent are 1–2 years of age, and 7 percent are under 1 year of age.

Since the vision of very young children is difficult to measure, it is not surprising that the "cannot classify" category comprises 41 percent of the combined total of "legally blind" and "cannot classify" for those under 1 year of age and 44 percent for the 1 year olds. This proportion decreases from 37 percent for those 2 years of age to 16 percent for the 6 year olds.

All records have not been classified as yet according to cause of the vision impairment. The following preliminary figures concerning three important causes of blindness are subject to modification as more records are added and diagnoses are scrutinized more carefully.

Results so far indicate that cases of blindness due to RLF, maternal rubella, and retinoblastoma are not infrequent. These three causes were responsible for 9, 6, and 4 percent, respectively, of the "legally blind" and "cannot classify" categories combined.

The proportion of RLF cases ranges from 12 percent for the 4 year olds to 6 percent for those age 1. It appears that the incidence of this condition may have reached an irreducible minimum. The National Society's Advisory Committee on Retrolental Fibroplasia is much concerned with this continuing problem and the possible need for further recommendations for clinical practice in the administration of oxygen to premature infants. A survey is now being made to collect information on incidence of RLF among 1967 births.

Perhaps some cases of RLF are unavoidable, since oxygen therapy is necessary as a life-saving measure for prematures with such conditions as hyaline membrane disease, respiratory distress syndrome, and cyanosis.

Rubella was responsible for 24 percent of the cases of blindness in 1 year olds and 20 percent in those under 1 year. In comparison only 5 percent of the 2 year olds, 2 percent of the 3–5 year olds, and 4 percent of the 6 year olds were blind due to this disease. In addition to congenital

cataracts, mental retardation and other handicaps are noted as part of the rubella syndrome. This will be commented on in the final report if data are adequate.

Retinoblastoma, a hereditary tumor of the retina, accounted for 8 percent of the cases of blindness in 2 year olds, 7 percent in those under 1 year, 5 percent in 3 year olds, and from 1 to 4 percent for the remaining ages.

The majority of the cases of blindness yet to be classified are expected to be in the prenatal influence category—hereditary or congenital not otherwise specified. Differences, if any, between this and the previous study in the incidence of specific anomalies will be analyzed. Infectious diseases and injuries will probably account for only a small percent of the cases.

In the 1950 study of preschool children, nearly 50 percent were blind due to RLF. This distorted the proportions for which other causes were responsible. In order to compare present preliminary results with those for 1950 we have made an adjustment to minimize the effect of RLF on the cause distribution.

If only 9 percent rather than almost 50 percent of the cases in 1950 had been due to RLF, rubella and tumors would have accounted for 2 and 5 percent respectively.

These adjusted proportions can be compared with those observed in the preliminary results of the present study. The 6 percent for rubella is three times higher than the adjusted proportion for 1950. The 4 percent observed for retinoblastoma, which comprises a majority of ocular tumors in young children, probably does not differ significantly from the previous study. If other causes occur at the same rate as in 1950, about 4 percent each for other infectious diseases and injuries, 64 percent for prenatal influence, and 9 percent other and unknown can be expected. Rates will be used in the final analysis to make comparisons of the various causes more meaningful.

This study of infants and young children with visual impairments is progressing well. Response has been good, and the participating agencies have been most cooperative in reporting promptly. Consequently, the study should be completed and results available while they are still current.

Processing of the reports is time-consuming, since a variety of records must be handled and the data are not as exact as desired.

Many of the cooperating agencies do not have adequate eye examination reports for the children receiving services. The National Society has emphasized for many years the need for good examination reports on school children with visual problems for guidance in planning educational programs for them. For older children in the study who are now in public or residential schools, eye examination reports, frequently on the form

recommended by the National Society, are available. However, many agencies, particularly those providing services only to preschool visually handicapped, have only case worker reports, letters from the examiners, and/or clinic or hospital reports.

In many instances report forms which are in use are poorly structured. Identifying information, such as birth date and sex, is not on the form, and other items valuable in an analysis of the causes of vision impairment are omitted.

In spite of the limitations imposed by the study procedure and inadequacies in the data reported the study should be worthwhile. The results will provide more information than is presently available on the serious eye problems of young children. They should be useful for planning service and prevention programs and determining research needs. Hopefully, they will lead to better reporting and more adequate data for future studies.

This is an example of the National Society's utilization of MRA register data. If all States had registers or the present MRA membership were more representative of the Nation this study would be much easier. In fact, it probably would not be necessary.

RUBELLA EPIDEMIOLOGY and VACCINES [1]

JOHN L. SEVER, M.D.[2]

THE EPIDEMIC of rubella in Australia 25 years ago resulted in the first recognition of the significance of this infection as a cause of defective children. It was following this epidemic that the ophthalmologist Sir Norman Gregg noted a high frequency of cataracts in children and recognized the association of rubella in the first trimester of pregnancy with damage to the eye (*1*). Since that time a number of studies have confirmed and extended these observations.

The frequency of abnormal pregnancy outcomes is approximately 50 percent if rubella occurs in the first month of pregnancy, 22 percent if it occurs in the second month, and 6 percent if it occurs in the third month (*2, 3*). Defects of the eyes are found in 15 to 20 percent of these children (*3*). In addition to the malformations of the eyes and heart, deafness, microcephaly, and mental retardation in the last few years we have become aware that congenital rubella may also result in hepatosplenomegaly, thrombocytopenia, jaundice, pneumonitis, radiolucency of the long bones, and chronic infection during the newborn period (*4, 5, 6*).

Rubella occurs primarily in the spring of each year in most countries. Epidemics generally occur at intervals of about 7 years (*7*). Some of the largest have coincided with periods of military mobilization. The majority of infections occur in children under 15 years of age and most of these are among school-age children (*7*). Rubella is less communicable than rubeola or varicella; and populations in semi-isolated areas frequently show a high proportion of susceptibles and may experience extensive epidemics at infrequent intervals. There is considerable variation in the reporting of rubella in different countries and cities. This is mainly due to the mildness of the disease produced by the virus and the fact that in most areas rubella is not a reportable infection.

In the United States data from the Communicable Disease Center since 1955 has been analyzed (*8*). Significant epidemics were noted in 1958 and in 1964–65. In the latter there was a clear movement of the disease from the Northeast to the West and South. For the most part

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this epidemic did not involve the west coast of the United States, Hawaii, and Puerto Rico until 1965 and was more intense in 1964 than in 1965.

The intensity and effect of the 1964 epidemic on pregnant women in the United States was studied by 11 institutions participating in the prospective Collaborative Study of Cerebral Palsy. In this study detailed clinical data were obtained for 6,161 pregnant patients and their children, and serial serum specimens taken throughout pregnancy were subsequently tested for antibody to rubella. Data now available from this study indicate that of the 6,161 pregnant women, 10 percent were exposed during the first trimester and 26 percent during the second and third trimester (*9*). Two percent developed clinical rubella, 40 percent of these in the first trimester. Ten percent of the women with clinical rubella in the first trimester had a child with congenital rubella syndrome which was recognized within the first month after birth. Clinical rubella was more frequent among white patients. Nonhousehold exposures were as likely as household exposures to lead to clinical rubella. Serological data corroborated the diagnosis of clinical rubella in 74 percent of the cases tested. Inapparent infection occurred in 6 percent of the women studied who were exposed to rubella in the first trimester but did not develop clinical disease.

Studies in military populations in the United States have further substantiated the seasonal occurrence of rubella (*10*). In general it occurs among recruits primarily in the spring. Of the recruit training centers in the United States the one at Ford Ord, Calif. consistently reports more cases of the disease than any other training station. Peak periods for rubella at Ford Ord were 1955, 1958–59, and 1964–65. The overall rate reported in military recruits in this country is 18 per 1,000 per year (*10*). One of the factors unique to Fort Ord is the high frequency of rubella among individuals from Hawaii. In 1960, for example, 77 percent of the recruits from Hawaii had rubella while at Fort Ord. The high frequency among recruits from other western States varied between 5 percent and 20 percent. Thus the disease occurs rather frequently among military recruits, particularly at Fort Ord, and is of concern in these training programs (*10*).

The epidemiology of rubella is undoubtedly influenced by the susceptibility of the population. This can be determined by serological studies of the frequency of antibody among individuals.

In a serological study of 268 individuals, who were in the general population of Montgomery County, Md. in 1957, the frequency of antibody to rubella was determined (*11*). The frequency increased from approximately 35 percent among children 1–10 years of age to 85 percent in the age group 16–25 years and older. This indicates that approximately 15 percent of the adults sampled were susceptible to infection with the disease. The major acquisition of rubella antibody occurred among school age children and this was several years later

than that of rubeola antibody. In all ages the frequency of rubella antibody was consistently less than that for rubeola.

In studies of pregnant women we have found that the frequency of those without antibody to rubella in the continental United States has varied between 19 and 32 percent in 11 collaborating study hospitals (*12*). There was a significantly greater frequency of individuals without neutralizing antibody among pregnant Negroes as compared to white patients and the number of women without antibody decreased significantly with increasing age. There was no correlation between the reported history of rubella and the presence or absence of antibody (*12*).

In Hawaii the frequency of pregnant women without antibody was considerably higher than in the groups studied in the continental United States. At the Kaiser hospital in Honolulu 58 percent of the women tested did not have neutralizing antibody and in a similar group of pregnant women studied in Hilo, Hawaii, 71 percent did not have antibody (*13*). Our recent studies in southern Japan indicate that in the population studied 34 percent of the pregnant women did not have neutralizing antibody (*14*).

Studies of isolated populations have indicated that when rubella occurs in these groups almost all susceptible individuals become infected. In an epidemic we have studied on the Pribiloff Islands off the coast of Alaska, for example, almost all of the individuals over 19 years of age had neutralizing antibody whereas almost none of those under age had antibody (*15*). When rubella was brought to the island by several girls returning from the mainland the epidemic involved almost every individual under 19 years of age.

Estimates have indicated that the 1964–65 epidemics of rubella resulted in 10,000 to 30,000 abnormal pregnancies. Based on the previous studies of Lundstrom, Decabon, and the Collaborative Perinatal Research, we can estimate that there would be 1,000–2,000 stillbirths and neonatal deaths; 3,000–5,000 children with visual damage; 3,000–5,000 with congenital heart disease; 1,000–3,000 with deafness; and 1,000–3,000 with mental retardation. There would be an additional 3,000–8,000 abortions and other abnormalities.

Several intensive programs are now under way at the National Institutes of Health for the development of a live attenuated vaccine for rubella; also studies are being conducted by eight manufacturers. Several other groups both in this country and abroad are also working on the live vaccine.

The goal of these programs is the development of a safe vaccine that can be given to prepubertal children and produce long-lasting immunity. This vaccine will probably be given by injection. It will be attenuated so that there will be no evidence of disease following inoculation. The vaccine must be nontransmissible. That is, the virus should not spread from

the inoculated child to other individuals. Early vaccine materials have shed extensively in the throat of the individuals who received them. Further studies are now in progress to produce greater attenuation and possibly eliminate shedding. Drs. Meyer & Parkman (*16, 17*) of the National Institutes of Health have described a vaccine that shows considerable promise. Recently Dr. Morris Hilleman (*18*) of Merck, Sharp, & Dohme reported that he has developed a vaccine that appears to show no shedding and thus may be considered particularly safe and nontransmissible. Unfortunately, none of these vaccines can be considered for administration to women of childbearing age since they have not been established as safe for pregnant women and the human fetus. Animal tests cannot establish this characteristic of the vaccine since the properties in humans may be quite different.

It is hoped that vaccines will be available and used before 1970. This is of particular importance since the next significant epidemic in this country may be expected in 1970 or 1971. One word of concern should be noted. If an epidemic does ocur in those years it is unlikely that the live vaccine material now under development could be given to women of childbearing age. None of these live vaccines can be considered safe for administration to women who may be pregnant. Thus there may be no way to protect susceptible women among the more than four million who may be expected to be pregnant in 1970 or 1971. It is possible, therefore, that a repeat of the events of 1964 and 1965 may ocur if the epidemic does develop at that time. This striking fact points out the need for the rapid development of vaccine material and the desirability of intensive programs for producing a killed vaccine that can be administered to nonpregnant susceptible women of childbearing age.

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IMPLICATIONS of a FUNCTIONAL DEFINITION of BLINDNESS

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VISUAL ABILITY can differ greatly even when visual acuity is identical and is recorded from identical visual charts. Consequently, many people in our country feel that a functional definition of blindness might be better than the present definition with which all are familiar. The precedent for adopting a functional definition is that several countries have used functional definitions which seem to work as well or better than a precise visual acuity or field limitation.

Visual ability, largely a function of experience and utility, differs from visual acuity which is dependent upon physiological principles. To understand why a visual acuity permits different visual abilities, we question two assumptions included in measurement of visual acuity; first, that 1 minute is the smallest visual angle the normal human eye can resolve; and, second, that the 5 minute angle is the normal threshold for perception and recognition of a form such as a letter. In Robert Smiths' "System of Compleat Optics," Dr. Hook assures us "the sharpest eye cannot well distinguish any distance in heaven, such as distance between stars which subtends a less angle at the eye than half a minute and hardly one in a hundred can distinguish when it subtends a minute." Since 1 minute of arc was the minimum required to perceive form it was assumed that the component parts of the object must subtend a 1 minute angle. Since this seemed reasonable and was simple and uncomplicated, it was adopted for clinical use. It probably is still the best clinical test for detecting defects in the optical system, but its limitations should be appreciated.

The vision sense consists of abilities to perceive light, form, and colors. In the laboratory the light sense and the visibility of a single line in a background can be measured quantitatively and the black line on a white background can be seen when it subtends only a half a second of an arc. The minimum separable in the laboratory actually has been measured to as small as 15 seconds, and a break in a line can be detected when it is as small as 3 seconds. Since these laboratory conditions are not simulated in life, they are not suited to measurements of visual acuity when clinical tests of visual ability are to be assessed.

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Other functions must be considered when one reads the Snellen Chart. One is the power of attention, a complex problem and not completely understood psychologically. Another is to fix or direct the eyes so the image falls on the retina's most sensitive part. Factors that further influence the visual acuity are refractive errors in the dioptric system, pupil size, test object distance from observer, extent of the surrounding field, illumination intensity, retina region's influence on visual acuity, legibility of letters in the Snellen Chart, and variability of the visual acuity itself.

Accommodation, binocular vision, and color perception are other visual characteristics not directly related to visual acuity. They have an *effect* on the visual acuity at times and also can *affect* visual ability directly. Visual ability, therefore, may depend on factors other than visual acuity, namely, impairment etiology, accommodation, binocularity, field (including form, size, and color), refraction, psychological aspects, etc.

Etiology brings us to consider visual loss, and its major areas which affect visual ability. These are the media; the retina's productive elements or their circulatory support in the choroid; the conduction elements, including nerves, pathways, or radiation; and the visual cortex where the images are received and recognized. Visual fields influence visual ability depending upon the degree of depression or scotoma density, size, and position. The visual field can be restricted in a variety of ways, for example, a central scotoma from nerve or macular lesions; peripheral constriction due to retinal, nerve, or choroidal damage; arcuate defects from retinal damage; and homonymous hemianoptic defects due to pathway, radiation, or cortical damage. Despite this, very few attempts have been made to rate fields or plot them meaningfully relative to visual function. Fields are very misleading as to visual ability, if interpreted too specifically since there are bizarre fields, and fields vary by object size, object color, eye examiner, subject's cooperation, and other variables.

Esterman (*1*) has suggested a simple and quick way to evaluate visual fields based on visual function, similar to the Snellen Scale for central visual acuity. Like the Snellen Scale, it expresses values in percent of an average standard. He feels that functionally, certain parts of the visual field have greater importance than others, and he has given these parts higher values based on the following three principles: the center scores higher than the periphery; the lower hemisphere scores higher than the upper; and the peripheral field near the horizontal meridian scores higher than other parts of the periphery. These principles are expressed by the grid in that the units are smaller, closer together and therefore more numerous near the grid's center, as well as in its lower hemisphere, and near its horizontal meridian. This makes the grid a relative-value scale which reflects the greater importance of these areas. Each grid consists of 100 units, each unit equals 1 percent. A simple count of units, or dots, within the field yields a direct score, in percent, of the field's function.

The central five degree area contains no dots, and is not scored because its function is expressed separately by the Snellen Scale. This standard for the perimeter grid is the same as the one that the American Medical Association Committee on Standards published in 1958. For the tangent screen grid it is the 25° isopter when a 2/1000 test object is used. Complete details on this method of measuring fields are presented in Esterman's published material. (*1*)

A perfect functional measure of visual field is difficult to create. Since Esterman did not consider acuity levels, colored test objects, or different size objects his method leaves something to be desired. However, the Rehabilitation Codes has adopted it as their standard to measure fields and visual impairment degree.

Clinical cases prove that visual ability can differ remarkably in persons with the same visual acuity. These differences are explainable usually on the basis of whether the mediae, the retina, the nerve, the pathways, the radiations or the cortex were involved. The differences that cannot be explained by any of these need further study and delineation.

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SOCIAL and REHABILITATION SERVICES for the VISUALLY IMPAIRED

D. C. MacFARLAND, Ph.D.[1]

UNDER ORDINARY CIRCUMSTANCES, a topic of this nature would necessitate a long preliminary discussion regarding the reorganization of HEW which led to the development of the Social and Rehabilitation Service. A prolonged description for most of you in attendance today would be quite redundant, since many of you are State directors or work in State agencies serving the blind that are directly affiliated with RSA and are cognizant through several conferences of the changes that have taken place. For those who are not quite so familiar, we should note that SRS has been formed by the bringing together of five large bureaus, all with the common purpose of serving people. These are Medical Services Administration, Administration on Aging, Assistance Payments Administration, Children's Bureau, and RSA. We are all very pleased that Mary E. Switzer, former Commissioner of the Vocational Rehabilitation Administration, was chosen as Administrator of the new agency.

Former Secretary Gardner had many reasons for the development of SRS. The following four, however, could be cited as the major rationale for the change: (1) a welding together of the large social welfare programs within HEW that provide direct services to individuals; (2) a division of social services from assistance payments; (The philosophy that stimulated this change grew out of a belief that the former definition of social services was too closely tied to a welfare program and, therefore, did not reach many of the people who could profit from them.) (3) the success of the vocational rehabilitation program over many years indicated that some of its approach would be beneficial if inculcated in the welfare program; (4) strengthening of regional operations—thus bringing direct consultative services closer to the State and local operations.

The new agency has only been in operation for 9 months, and, therefore, any attempt at reporting the efficacy of the approach would be premature on my part. However, I have been asked to comment on what SRS is doing for the blind and visually handicapped. We are pleased to

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note that for the past several months we have been working with all constituent agencies to develop a concerted service program for the blind. The initial plan has only been issued to the States within the past 10 days. Therefore, we are still in the data gathering stage but hope to have a few pilot programs in operation early in the fall. Basically, the plan calls for working with existing public and private agencies serving the blind and helping them make better use of funding and technical support that can be obtained through full utilization of the resources of our five administrations. Heretofore, our efforts have been concentrated on serving clients who had a vocational rehabilitation potential. Even though this definition by regulation can be construed to include homemakers, usually we were not able to serve the older blind citizen nor the preschool or school age child. If we are successful in exploiting all potential resources, agencies for the blind should be in a position to broaden their activities to meet the many service gaps that now exist. For example, expanding prevention of blindness services through the expedious use of title XIX. Using the same mechanism, we can provide diagnostic evaluation and medical services for preschool and school age children. Ancillary services for these children, especially for those that have multihandicapping conditions in addition to blindness, where such services cannot be made available by the Office of Education or State education departments will also be provided under another section of the proposed plan.

Your conference this morning pinpointed difficulties that we can expect as a result of recent epidemics of rubella. This is only one medical condition that complicates the disabilities of blindness. Recent studies have shown that we can expect more than 50 percent of all blind children to have additional major handicaps. With this in mind, we must gear our services and plan our programs to meet these future needs.

Even though we do not have an accurate population census of the blind, we have been familar with the fact for many years that more than 50 percent of our blind population are above age 60. Special service programs for these persons must be greatly expanded. What we are doing now is pitifully inadequate. Planned social services to expand optical aids clinics, to develop recreational facilities so that they can be used by older blind citizens, and to provide instruction in mobility and activities of daily living are but a few of the many activities in which we must become involved on a very large scale within the next few years. In order to do this, all present resources of public and private agencies will be taxed severely; new personnel, especially in the subprofessional field, will be urgently needed; and I think it can be safely said that the job can never be satisfactorily accomplished unless we develop a massive program for utilizing volunteer workers in every area of the country.

There is little more that can be said at this time regarding our SRS plan for services to the visually handicapped and the blind. We are doing our utmost to push it forward as rapidly as possible and hope that at the

time of your meeting next year we will have some very tangible results to report.

While we recognize our new and rather awesome responsibilities, I do not want to leave the impression that vocational rehabilitation services for the blind will be neglected.

We are continually evaluating the job market, opening new employment frontiers, and developing training facilities to prepare blind persons to take their places as competitive workers in this rapidly developing technological society.

During the past year, we have had notable success in increasing employment in the professional, subprofessional, and clerical fields within the Federal Government. We shall continue our efforts in this area and expand them to include employment in the State and in the local community.

You are all familiar with the phenomenal success blind persons have achieved in training for and working as computer programmers. We now have five accredited schools around the country where blind students are enrolled along with their sighted peers. Thus far, we have heard of no one who is having any difficulty achieving satisfactory placement.

Within the next few weeks, we expect to initiate a new project that will develop employment opportunities in the same field (computer programming) at a lower level in data processing.

Our agency has joined with the Internal Revenue Service to make a concerted effort to train and place blind persons to work with that organization in a variety of jobs that have been determined practical for blind persons.

We have also begun a 3-year demonstration project with the National Industries for the Blind. The program is essentially designed to review many of the items now purchased in large quantities by the Federal Government and reengineer the machine, assemblying, and packaging operations employed in the production of these articles. The changes make it possible for multihandicapped blind persons to perform the various jobs. Until recently, most of these individuals were never considered for competitive employment. The experiment thus far has amply indicated that when the proper job is selected, production components engineered, and the multihandicapped blind person thoroughly trained, he can not only produce the item but can earn at a rate equal to or better than the minimum wage. We feel certain that several thousand such persons will be provided employment in sheltered workshops through this effort alone.

We are also evaluating new jobs in the field of recreation which we believe will provide employment for many blind persons now living in the rural areas without necessitating moving them to already overcrowded urban situations. Last year we joined with the National Education As-

sociation and several superintendents of schools to develop new employment opportunities for blind persons teaching in public schools.

All these efforts and many more are designed with three purposes in mind—to provide maximum employment opportunities for all blind persons who can be trained to compete and are desirous of employment; to develop training programs in employment areas that have stability and apparently will not be automated out of existence witihin the next decade. The final reason, but by no means least important, is to make certain that our vocational rehabilitation program is not only contributing to a better life for blind persons but is also geared to meet some of the critical manpower shortages.

With our increased efforts in vocational rehabilitation and greatly expanded role in the provision of social services to all blind persons, your work in developing a model reporting registry in every State becomes very significant to us. We salute you for what has already been accomplished and hope it will be possible for you to develop a total registry for all blind persons in every State within the next few years.

ECONOMIC BENEFITS to the NATION from PROVIDING VISUAL ASSISTANCE DEVICES to ITS BLIND

KENNETH TROUERN-TREND [1]

OUR NATION should benefit materially from furnishing therapy or prosthetic devices to its blind. It, therefore, should consider developing an artificial visual system despite the enormous problems in engineering, physiology and psychology that must be solved to get it. The Nation should invest in this only after it has determined what is needed, what is technically feasible, what resources must be committed and the overall economic impact to be expected.

A study [2] which we recently completed for the National Institute of Neurological Diseases and Blindness (NINDB) reviewed the available statistics on how many blind people the U.S.A. has and thus the magnitude of the problem. It also analyzed the costs and benefits of providing visual assistance devices. We collected data for estimating the number blind and extrapolated it to represent the whole country and its total blind population. All identified blindness statistics were reviewed to categorize the blind population for developing visual assistance devices.

The study proved that the Model Reporting Area (MRA) for Blindness is the only adequate source for estimating the magnitude and composition of our Nation's blind population. Upon contacting all non-MRA States, we obtained adequate data only from New York, which since has become an MRA member. MRA statistics are very good for additions to registers in a year, but less reliable for the total number in them at end of a year. Most MRA registers were developed from registers the States prepared for their own use before joining MRA and include the records of persons blind for several years. Some were registered without diagnosis of blinding affection and its etiology, and even now lay persons report additions to registers. Additions to a register in a year are equivalent to about 10 percent of its total population at the year's end. Since approximately the same number are removed from a register as were added, it takes about 10 years to replace a registered population,

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[1] Senior Research Scientist, Health Systems Research Laboratory, The Travelers Research Center, Inc.

[2] A Cost-Benefit Analysis of Providing Visual Assistance Devices for the Blind.

with a new one. Therefore, it would take 10 years to purge a register of inadequate diagnoses, if the individuals with such diagnoses do not have their eyes reexamined.

Only MRA generates adequate data for enumerating and categorizing the blind population. Lack of adequate data motivated MRA's initiation and its development. The present situation reflects the success achieved. How many blind people the MRA States have in their registers is known. However, the percent of the blind population that they have failed to register for various reasons is unknown. To establish this percent it is necessary to know the size of the blind population which never has been established exactly because it is very difficult and expensive to find blind persons who have not been registered. Complete registration is desirable and the present level within the MRA probably is very high. Significant tendencies are not likely to be distorted or obscured by use of MRA statistics. If present MRA standards are implemented fully, every blind person should be registered eventually. It is unprofitable to pursue this as an end in itself. Even great expenditure of effort to register every blind person would only approximate the latest records of a rapidly changing population. Additions to MRA registers are at a rate of one per hour, and removals from them are at nearly the same rate because of death, loss of contact with the registering agency, etc. The intervals between updating would have to be very short to get a continuous picture in this dynamic system. The best possible register must be somewhat out of date.

We have not identified therapy or visual assistance devices, but have assumed that blind persons can be restored to sighted visual acuities by appropriate means. Visual assistance devices were matched with responsive individuals by extrapolating NINDB's published blindness statistics to represent the U.S.A.'s total blind population by visual acuity, etiology and affection. Within each blindness category, we estimated the number the U.S.A. has by their age and sex. Thus, if a particular blindness category can be alleviated, we could determine how many could be helped in each age group. Extrapolation of MRA statistics yielded the estimate that the U.S.A. had about 292,000 legally blind persons in 1966. Previous work suggested that this total was about 420,000.

The importance of knowing how many blind the entire country and each State has, stimulated others to estimate these numbers from statistical parameters of populations. Dr. Ralph Hurlin's estimates which he made several years ago have been important and still are. The blindness rates now available from individual MRA member States enable us to estimate how many were blind at a year's end and how many were blinded in that year in a population with specified characteristics. New rates can be calculated when new values become available for the stipulated population. These calculations can be made with a desk calculator.

The estimated blindneess rates we derived differ less between States than previous estimates did because the population parameter values have leveled off recently and our estimates are independent of the population's race structure. Since there is no physiological evidence for different blindness rates in whites and nonwhites, the rate differences probably result from economic and environmental factors confronting each group. Race was omitted from our study because its significance seemed overweighted, and it might have led to improbably high proportions of nonwhites.

Sight restoration will have a signficant economic impact because it will reduce the public support blind persons need and increase their probable income. The support that a blind person needs now is about $1,700 a year. Much of this support is not a direct financial contribution but it is convenient to consider it this way. Our computer program calculated the present (discounted) value of the lieftime support income provided to the blind and the potential lifetime earned income of those restored to sight for each blindness category and each age and sex group within it. Benefits were related to their costs by balancing the cost of necessary therapy and equipment against present support costs no longer needed and the potential future income of those with restored sight.

The potential lifetime income of the 1966 blind population, if restored to sight, has a present value of about $5.7 billion. The support costs for this population, without sight restoration, have a present value of about $5.5 billion. Their sum, which is more than $11 billion, is the present value of restoring all blind persons to sight. The costs of these benefits are the expenditures for developing and applying necessary procedures and for rehabilitating and training the formerly blind to ensure success in the sighted world.

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